Adherence to antiretroviral treatment in Zambia: a qualitative study of patients and health professionals' views.

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ABBREVIATIONS AND ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ART	Anti Retroviral Therapy
ARV	Anti Retroviral
CBoH	Central Board of Health
CHAZ	Churches Health Association of Zambia
CHEP	Copperbelt Health Education Project
DHMT	District Health Management Team
FGD	Focus Group Discussion
GFATM	Global Fund to Fight AIDS, Tuberculosis and Malaria
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immuno - deficiency Virus
IEC	Information, Education and Communication
MoH	Ministry of Health
NGO	Non Governmental Organization
OPD	Out Patients Department
STD	Sexually Transmitted Disease
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization
ZDHS	Zambia Demographic and Health Survey

Abstract

Background:

Adherence to antiretroviral therapy (ART) is important for effective treatment. Little is known about barriers and facilitators to ART in Zambia. The aim of the study was to gain knowledge about adherence to antiretroviral treatment among patients and health care professionals in Zambia, in order to identify interventions that may be efficient in increasing patients' adherence to antiretroviral treatment.

Methods:

I conducted a qualitative study in Kitwe and Masaiti districts on the Copperbelt Province of Zambia in 2006. I used a combination of in-depth individual interviews and focus groups with patients on ART, health care professionals working in ART clinics and other informants. The material was analysed using qualitative methods.

Results:

My study identified barriers and facilitators which were diverse in nature and belonged to a wide spectrum of factors which include patient related, health service related, socio-economic and cultural factors. These include lack of communication and information about ART, inadequate time during consultations, follow up and counselling, forgetfulness, stigma, discrimination and disclosure of HIV status, lack of confidentiality in the treatment centres, lack of nutritional support, feeling better, prospects of living longer, family support, information about ART, support for income generating activities and transport..

Conclusion:

This study suggests a multiplicity of factors and issues which need to be taken into consideration when providing ART. Further research is needed including participant observations to capture the actual interactions between patients and their health care providers. Also, future studies should assess the magnitude of non adherence to ART in Zambia using quantitative measures. My findings can inform the design of interventions to promote adherence to ART.

CHAPTER 1: INTRODUCTION

1.1 BACKGROUND

The last two decades, HIV/AIDS has continued to spread across all continents causing the death of millions of adults in their prime age, disrupting and impoverishing families and turning millions of children into orphans. HIV/AIDS affects the most productive segments of the populations, and the epidemic has thus tremendously reduced workforces and reversed many years of economic and social progress and has in some cases posed threat to political stability. According to the Joint United Nations Programme on HIV/AIDS (UNAIDS), there were about 39.5 million people living with HIV by the end of 2006. Out of these, 37.2 million were adults and 2.3 million were children below the age of 15 years. There were 4.3 million new infections in 2006 (1) . In Sub – Saharan Africa about 2.8 million people were infected with HIV and 24.7 million people were living with HIV. Despite recent improved access to antiretroviral treatment (ART) and care in many of the world's regions, the epidemic claimed 2.9 million lives in 2006 (1). In 2001, Heads of States and Representatives of Governments met at the United Nations General Assembly Special Session and issued a declaration of commitment to ensure a comprehensive and effective global response to the epidemic. The 2001 declaration endorsed care, support and treatment for people suffering from HIV/AIDS (2).

1.2 GLOBAL PERSPECTIVES OF ANTIRETROVIRAL TREATMENT

The advent of potent Anti Retroviral Treatment (ART) in 1996 led to a revolution in the care of patients with AIDS in the developed world. Although this treatments is not curative and also presents new challenges with respect to side effects and drug resistance, it has dramatically reduced rates of morbidity and mortality, have improved the quality of life of people with HIV/AIDS and have revitalized communities (3) Moreover, HIV/AIDS is now perceived as a manageable chronic illness rather than as a plague (4). Unfortunately, most of the 39.5 million people currently living with HIV/AIDS reside in developing countries and do not share this improvement in prognosis (3).

There has been a dramatic change in the global HIV/AIDS landscape with increased attention to care, treatment and support. On the World AIDS Day 2003, World Health Organization (WHO) and UNAIDS launched an initiative that aimed to treat 3 million

people in the world's 50 heavily burdened countries by the end of 2005, called the "3 by 5 initiative". WHO estimated that at the end of 2003, some 6 million people in developing countries were in immediate need of life sustaining ART. However, only 400,000 people received treatment over a third of them in Brazil. At the UN General Assembly High Level Meeting on HIV/AIDS on 22nd September 2003, WHO declared that the lack of access to HIV treatment was a global health emergency (5). The last years there has been an increase in the number of countries scaling up ART programmes in developing countries due to increased resources from local governments and the donor community in initiatives like the Global Fund to Fight HIV/AIDS, Tuberculosis and Malaria, World Bank and the United States President's Emergency Plan for AIDS Relief.

1.3 THE SITUATION IN ZAMBIA

Zambia is one of the countries with the highest prevalence of HIV in the world. The Zambia Demographic and Health Survey (ZDHS) of 2002 found that the prevalence among adults aged 15 – 49 years was 16 %. The mode of transmission is predominantly heterosexual. Mother to Child transmission is also significant. The peak in AIDS cases among women is 20 – 29 years and among men is 30 – 39 years old, suggesting transmission from older men to younger women. The prevalence of HIV is significantly higher among women (18%) than men (13%). Women account for 54% of all individuals living with HIV/AIDS in Zambia (6). The epidemic is estimated to have left at least 600,000-orphaned children (7).

In 1986 the government established the National AIDS Prevention and Control Programme, which focused on eight operational areas namely Tuberculosis and Leprosy, Information, Education and Communication (IEC), Counseling, Laboratory support, Epidemiology and Research, Sexually Transmitted Diseases (STD) and Clinical care, Programme management and Home based care (7). Zambia has adopted a multisectoral approach to prevention and mitigation of the HIV/AIDS epidemic. All Government sectors are involved in the response and so is the private sector, Non Governmental Organizations (NGOs), Community Based Organizations (CBOs), Church Organizations and the community at large. In 2002, the Zambian Government took a policy decision to make ART widely available to everyone needing treatment and allocated 3 million USD

to purchase ARV drugs for 10,000 people, to be provided through the public service. The Provision of ART was recognized as an integral component of the multisectoral response to HIV/AIDS. This was provided on a cost-sharing basis. In July 2005, the Ministry of Health started providing free treatment to people eligible for ART. The ART programme has been scaled up from the two initial pilot hospitals to 72 public health facilities across the country. The new policy includes free drugs, basic laboratory tests and CD4 counts (8) The goal of the ART Program is to reduce HIV related morbidity and mortality through universal access to ART for people living with advanced HIV infection in order to reduce the socio – economic impact of HIV/AIDS.

1.4 COUNTRY PROFILE

Source: Central Statistical Office, Lusaka, 2006

1.5 GEOGRAPHICAL LOCATION

Zambia is one of the countries in Southern Africa. It shares boarders with the Democratic Republic of Congo and Tanzania in the north, Malawi and Mozambique to the east, Zimbabwe and Botswana to the south, Namibia in the south-west and Angola in the west. It lies between 8 and 18 degrees south of the Equator and between 20 and 35 degrees east of the Greenwich Meridian. Zambia is landlocked, covering an area of 752,612 square kilometers (about 2.5% of Africa's total surface area). Zambia is divided into nine provinces and has a total of 72 districts designated for administrative purposes (6).

1.6 POPULATION AND DEMOGRAPHIC CHARACTERISTICS

Zambia has a young population of 10.3 million people. About 65% of the population lives in rural areas. Fertility rate is 2.9 children and annual growth rate of the population is 2.9%. By the age of 18, almost half of women aged 15 to 49 have had their first birth. Almost 50% of the population is less than 20 years of age, the most vulnerable to HIV (6). The population by sex is evenly distributed with women accounting for 50%. Zambia is a country endowed with many languages. Officially, there are 72 ethnic groups with each of them speaking a dialect of the seven major language cluster groups. English is the official language of instruction in schools, although there are other languages taught in schools in specific provinces. A large segment of the population remains uneducated and illiterate. In the census of 2000, only 55.3% of the population aged 5 years and above (6).

1.7 ECONOMY

Zambia has a mixed economy, with mining being at the centre stage of economic activities. In recent years, the Government has put agriculture and tourism as other important economic activities. Zambia is abundantly endowed with minerals and other natural resources that are required to stimulate economic development. Notwithstanding this, about 87% of the population lives below the income poverty line of $2 per day and about 64% live below the national poverty line of $1.08 per day. It is also estimated that 49% of the entire population are undernourished. In the 2006 Human Development Index Ranking, the country with a GDP per capita of $877 was ranked 165 out of 177 countries (9).

1.8 HEALTH SECTOR ORGANISATION AND MANAGEMENT

Since 1992 Zambia has been implementing health sector reforms, aimed at improving health service delivery and the health status of the population. The vision of the reforms has been to " provide the people of Zambia with equity of access to cost effective, quality health care as close to the family as possible" (10). The underlying principle of these reforms was decentralization of health service delivery through the delegation of key management responsibilities from the centre to the district and hospital levels. Decentralization also aimed at shifting resources from the centre to operational levels,

where healthcare delivery services were conducted. The reforms also emphasized the importance of community participation in the management of health services and the need for a well motivated and remunerated work force. Implementation of the reforms has been through a series of National Health Strategic Plans, of which the country is in its fourth plan covering the period 2006 – 2011 (10). In this respect, two parallel, but complimentary organizational structures were introduced, namely the popular structures for public involvement and participation in the decision – making process, and the technical and management structures, designed to ensure that health services were implemented and managed in a manner that was technically sound and conformed with best practices. The popular structures created in that process included: the Central Board of Health (CBoH) board, at national level; Hospital Management Boards, at hospital level; District Health Boards, at district level; and the Neighborhood Health Committees and Health Centre Committees, at community level.

The technical structures that were established included: the Management Teams at Ministry of Health (MoH) and CBOH, at national level; Hospital Management Teams, at hospital level; and District Health Management Teams, at district level. Further, the Provincial Health Medical Offices were reconstituted into Provincial Health Offices. There has been a recent repeal of the National Health Services Act (NHSA 2005), leading to the dissolution of CBoH, Hospital and District Management Boards. Following this decision, the health sector is undergoing a comprehensive restructuring process through which the functions of MOH and CBOH have been merged and the management and control of all the public health facilities and services now fall directly under MOH through the Provincial Health Offices. In order to ensure continued popular public participation in the management of health services, the hospital and district management boards are in the process of being replaced by advisory councils. Despite this vision, the health sector is still facing significant challenges including the high disease burden, compounded by the HIV/AIDS epidemic. The performance against the Millennium Development Goals has not been satisfactory. The country has one of the highest dependency ratios in the world and is also among the most urbanized countries in Sub – Saharan Africa, with approximately 36% of the population living in urban areas. Poverty levels have remained high, estimated at 68 % in 2006 (9). As a result of high

levels of poverty, preventable and treatable diseases have taken an enormous toll on the poor, increasing pressure on the already constrained health sector.

1.9 HEALTH CARE PROVIDERS

Health care in Zambia is provided by government institutions, the Churches Health Association of Zambia (CHAZ), mining companies, Parastatal organizations, private clinics and traditional healers. The structure of public health facilities run by the government comprises health posts as the smallest unit, health centers, level one hospitals, level two hospitals and level three hospitals (11).

Table 1: Summary of existing health facilities in Zambia

Type/level	Government	Mission	Private	Total
Hospitals	53	27	17	97
Health Centers	1052	61	97	1210
Health Posts	19	0	1	20
Total	1124	88	115	1327
Source: CBoH, Health Institutions in Zambia: A listing of Health Facilities according to levels and locations, 2002 (11).				

1.10 INSTITUTIONAL FRAMEWORK FOR DELIVERING ART IN ZAMBIA

Administration of ART is being integrated into the existing national health care system (12). ART is part of the essential health care package with components that are being delivered at all levels of the health system. The various levels, stakeholders and institutions involved in the delivery of ART include the following:

District Health System – The District Health System provides primary health services at the district level, preventive and health promotion services and clinical services. The following levels of health care provision are at the district level, the district hospital (level 1 hospital), Health Centre, and Health post. At the Community level NGOs,

Community Based Organizations, the Church, Community Based Distributors and Traditional Birth Attendants supplement health delivery.

Private Sector – Private sector plays a significant role in providing medical services in Zambia. Private for profit health services are mainly concentrated in urban areas. The private sector includes private clinics and hospitals, private pharmacies and companies which provide health services to a greater or lesser extent to their employees who require ART.

Hospital Management Boards – These provide health services through large public hospitals that are outside the district health system. Included here are second and third levels hospitals. The second level hospitals provide clinical services in Pediatrics, Internal Medicine, Obstetrics and Gynecology and General Surgery as well as advanced diagnostic services. This level receives referrals from and provides technical support to the district level. It conducts training for health workers. These are located at regional level. Under the authority of the Hospital Management Boards, five hospitals have been identified to provide tertiary services. These hospitals provide specialized services in clinical disciplines including Pediatrics, Internal Medicine, Obstetrics and Gynecology, general Surgery, radiology, specialized laboratory as well as other specialized diagnostic services. The Copperbelt province has three of such hospitals.

Ministry of Health – MOH provides majority of all health services in Zambia. It interprets and implements health policies develop guidelines, including treatment and preventive protocols, monitor performance of health facilities through provincial health offices, ensure steady flow of drugs, medical and non medical supplies. The MOH also retains the functions of resource mobilization, policy formulation, strategic planning and bilateral and multi lateral international cooperation.

National HIV/AIDS/STI/TB Council – This oversees policy interpretation and implementation, coordination of HIV/AIDS/STI/TB activities, donor and stakeholder

coordination, resource mobilization and disbursement and monitoring and evaluation of HIV/AIDS/STI/TB programmes and activities.

Medical Council of Zambia – is responsible for overall quality of medical practice in the country including the quality of medical facilities. This includes accreditation of health facility to ensure that all facilities that are providing ART provide the services within the minimum required standards. The Medical Council of Zambia certifies health care providers of HIV care and ART services.

National Food and Nutrition Commission – National Food and Nutrition Commission is responsible for providing nutritional support guidelines and implementation of nutrition based interventions.

1.11 POLICY AND TREATMENT GUIDELINES

The goals of ART in Zambia include reducing the amount of HIV viruses in the body, support and helping the immune system, improving the quality of life, reducing HIV related illness and deaths and reducing the risk of HIV transmission to others. Provision of ART is based on the following criteria; must be HIV infected, must meet clinical and laboratory criteria of symptoms, viral load and CD4 count, must understand the potential side effects and the importance of strict adherence (13). The Zambian government has since August 2005 been offering free ART to the people which is accessed through the public health institutions. This decision was arrived at as a result of the overwhelming poverty levels on the other hand and the high cost of accessing ART on the other hand. The National ART programme adopted the WHO Public Health Approach treatment guidelines for resource limited settings. Zambia has adopted standard multi drug regimens in order to help minimize the emergence of drug resistance among the patients (13). The guiding principles for provision of ART according to government are as follows:

- ART will be provided free in all public health facilities
- Registration fees will still be applicable

- Free services in this context shall include all aspects of ART including Antiretroviral drugs, laboratory services and tests like Full Blood Count, Liver Function tests, Total Lymphocyte Count, CD4 Cell Count, Rapid Plasma Reagin test, Sputum examination and other related services.
- Refugees shall have free access to ART
- Foreign nationals, excluding refugees shall pay full cost for ART

Table 2 lists the recommendations for initiating ART in Zambian adults and adolescents:

Table 2. Recommendation for ART in adults and adolescents in Zambia

Clinical Stage	CD4 Available	CD4 Not available
I	CD4 Guided	Do not treat
II	CD4 Guided	Total Lymphocyte Count less than 1,200 mm3
III	Consider CD4 Count	Treat
IV	Treat	Treat

Source: Scaling up Antiretroviral Treatment for HIV/AIDS in Zambia. Policy and Operational Guidelines. Ministry of Health; Ndeke House; Lusaka; 2004.

When CD4 Cell Count is below 200 mm3, treatment should be initiated irrespective of the clinical stage. Again if the CD4 Cell Count drops between the levels of 200mm3 to 350mm3, consideration for treatment should be done if there is more than one sign, before the CD4 count drops down below 200. When the CD4 count is above 350 mm3, treatment should be postponed if the patient is not showing any symptoms.

1.12 RATIONALE OF THE STUDY

Adherence or compliance with therapy is one of the most complex areas of ART management. While the development of resistance to ART is regarded as the greatest threat to our current armamentarium of drugs, poor adherence, which is the major cause of the development of resistance, is given little attention in planning an antiretroviral programme (14). Adherence to ART is well recognized to be an essential component of

individual and programmatic treatment success (15). Studies of drug adherence in the developed world have suggested that higher levels of drug adherence are associated with improved virological and clinical outcomes and that rates exceeding 95% are desirable in order to maximize the benefit of ART (16).

Access to ART has become feasible in developing countries due to reduced costs of antiretroviral drugs and increased resource allocation by various governments and other initiatives. There has been fears from the developed countries of wide spread, unregulated access to antiretroviral drugs in Sub Saharan Africa which could lead to rapid emergence of resistant viral strains, spelling doom for individual patients, curtailing future treatment options and leading to transmission of resistant strains. While there were few skilled Physicians in the use of antiretroviral drugs, the health infrastructure was incapable of monitoring viral load, immune status, or side effects of the drugs. Drug procurement and distribution systems were said to be weak and drug interruptions were likely. There were no monitoring systems in place to check on drug adherence or drug effectiveness (17).

It is estimated that there are 100,000 new infections of HIV in Zambia annually. At least 99,000 people die of AIDS related deaths annually in Zambia (18). HIV/AIDS affects the most productive age group required for economic development, and has impacted negatively on all sectors of national development and has reversed developmental gains achieved by the country since independence. Zambia has embarked on a massive scaling up programme for ART. According to the Central Board of Health , the number of people accessing ART in the last two years has increased by over eight fold from 3,000 in 2003 to over 43,771 by the end of 2005 (19). HIV/AIDS treatment scaling up is a priority according to the National HIV/AIDS/TB/STD Strategic Plan (20).

A recent report from a study conducted at the University Teaching Hospital in Lusaka has raised concern about the emergence of resistant HIV strain to first line ART regimen in Zambia (21). Because adherence of patients with HIV to ART is essential for both clinical effectiveness and public health, research in adherence to ART in Zambia is critical. Little is known about factors that influence adherence and non adherence to ART in the Zambia. Zambia offers free treatment to her patients and the treatment support is largely supported by funds from the donor community and therefore, the emergency of resistant strains to the first line treatment is a serious development

which will make the sustainability of the programme not only more costly but a public health challenge.

1.13 AIM OF STUDY

The aim of the study was to gain knowledge about adherence to antiretroviral treatment among patients and health care professionals in Zambia, in order to identify interventions that may be efficient in increasing patients' adherence to antiretroviral treatment.

1.14 Specific Objectives

- To investigate how health care professionals explain adherence and non adherence to antiretroviral treatment in patients.
- To investigate how patients who are on antiretroviral treatment explain adherence and non adherence to antiretroviral treatment.
- To identify factors that can inform interventions to increase patients' adherence to antiretroviral treatment.

CHAPTER 2: LITERATURE REVIEW AND THEORETICAL FRAMEWORK

2.1 THE NOTION OF ADHERENCE

There is no universally accepted definition of medication adherence. With respect to HIV/AIDS care specifically, adherence to HIV medication has been defined by Jani as "the ability of the person living with HIV/AIDS to be involved in choosing, starting, managing and maintaining a given therapeutic combination medication regimen to control viral (HIV) replication and improve immune function" (22). The term adherence has also been defined as 'the extent to which a person's behaviour (in terms of taking medications, following diets, or executing life style changes) coincides with medical or health advice' (23).

However, Trostle et al. suggests that behavior often labeled 'non compliant' by physicians can be seen as reasonable attempts by patients to manage their illness outside the examination room (24). Non compliance from the patient's perspective is often rational, understandable and justifiable given that social forces unrelated to the biomedical model influence his or her behavior. Trostle argues that much of the literature on non compliance emphasizes the medical profession's conviction that the problem lies in the patient's behavior or in the doctor - patient relationship (24) .The evident disparity between patient's needs and the physician's professional interests coincides with much speculation about the power of the biomedical establishment, especially it's power to legitimate concepts of health and illness and to configure the patient's subjectivity. According to Conrad , most theories locate the sources of non compliance in the doctor – patient interaction, patient knowledge or beliefs about treatment and to a lesser extent, the nature of the regimen or illness (25). Conrad offers an alternative perspective on non-compliance with drug regimens, one situated in the patient's experience of illness. Using data from a study of experience of epilepsy, Conrad argues that from a patient centered perspective, the meanings of medication in people's everyday lives are more salient than doctor – patient interaction for understanding why people alter their prescribed medical regimens.

2.2 IS NON ADHERENCE A PROBLEM?

Antiretroviral drug resistance is a major challenge to treatment programmes for both developed and developing countries. Currently, approximately 10% of new HIV – 1 infection in the United States of America and Europe involve viral strains exhibiting resistance to at least one drug (26). According to WHO, only 50% of patients who suffer chronic diseases like HIV/AIDS, diabetes and hypertension adhere to treatment recommendations (27). In developing countries, when taken together with poor access to medicines, poor adherence is threatening to render futile any effort to tackle chronic conditions such as HIV/AIDS. Of those patients suffering from HIV/AIDS, approximately one-third take their medication as prescribed. Studies of HIV/AIDS have reported low adherence rates, similar to those seen for other chronic diseases. Sub optimal adherence rapidly leads to resistance, which can then be transmitted to other people (28,29).The potent and new combinations of ARV agents, known as Highly Active Antiretroviral Therapy (HAART), have proven efficacious in reducing viral load and improving clinical outcomes. However, the large number of medications involved, the complicated dosing requirements and the sub optimal tolerability make adherence difficult (27). Studies of ART in developing countries show that there is already resistance circulating among patients who are starting their first line 'official' course of therapy (21) . In a study to assess the level of compliance to ART among AIDS patients in Nigeria, only 54% of the patients took at least 80% of the drugs prescribed. Main reasons for non-adherence to medication include non-availability of the drugs, forgetfulness and lack of funds (30). A study conducted in South Africa showed excellent adherence in a high proportion of HIV – 1 infected adults receiving ART in a resource limited setting. Despite the low socio – economic status and the low to mid levels of education attainment of the study population, 88% reported ART adherence >95 % (31).

In Zambia, a recent laboratory study conducted at the University teaching hospital, Lusaka had confirmed the drug resistant strain, and its emergence is clearly an indication that people are not being consistent with their medication (21). An unpublished operations research report by the International HIV/AIDS Alliance in conjunction with Horizons Project on a pilot intervention for HAART in Lusaka and Ndola Central

Hospitals found that information on ART at the start of treatment was not adequate, patients adjusted and devised their own routines and reminders of pill taking, fear of organ damage were identified as some of the reasons for non adherence to ART (32).

Non-adherence can take many forms. The patient may simply fail to fill the prescription. If the prescription is filled, the patient may incorrectly time the medication or take wrong dose because he or she misunderstood or forgot the health professional's instructions. Patients may also forget a dose completely or prematurely terminate the medication. Moreover, patients may self adjust their regimen because of side effects and toxicity or personal beliefs (27). Reviews of HIV/AIDS medication regimen adherence literature have chiefly focused on a variety of factors which include characteristics of the medication regimen, social factors, psychological, patient- provider relationship, treatment regimen, disease and clinical setting (33).

2.3 SERVICE RELATED FACTORS

Patient adherence to ART is a complex phenomenon that can be affected by a number of variables. Some studies suggest that good health care provider-patient relationships are associated with better adherence. Patient education, especially towards understanding the medication regimen and its requirements is probably the chief health care provider influence towards better adherence (34). Good communication between patient and health care provider about patient's life style and preferences can improve ART adherence (35,36). The cost of treatment has also been identified as a barrier to adherence, leading to extended drug holidays. Cost was a barrier that prevented medication purchase, therefore, interfered with adherence or self imposed drug holidays (37,38). Some studies conducted in developing countries have documented non availability of drugs in health facilities as a contributing factor to non adherence to ART (30,39). Inadequate knowledge about how to take medication has been recognized as a barrier to patient adherence to ART. Patients do not adhere to their treatments because of not knowing proper ways of taking their pills (37).

2.4 PATIENT AND TREATMENT RELATED FACTORS

The complexity of adherence to ART by patients has been documented as a daunting challenge to adherence interventions. Reconciling medication schedule with demands of shift work has been identified as a barrier to adherence (40). Industrial and health workers in particular, were identified in other studies as often facing a moving work schedule where work, eating and sleep times changed frequently. Fitting together the demands of timing several different medications with meal times, sleep and in some cases, highly regimented work, where little time flexibility is permitted on the job, creates cross-cutting pressures that pose barriers to adherence and generate conditions for forgetting (41). Concurrent use of a substance while taking ART leads to patients not adhering to their medications (42-44). Substance abusers were least likely to cope well with other demands in their lives. They experienced low self-esteem, low sense of control over their lives and fatalism about HIV and life in general. Such patients had impaired ability to adhere to medications (44).

Side effects of ART have been identified to cause adherence problems in patients. Patients experienced side effects like nausea, fatigue, diarrhoea and vomiting, tingling and as such made medication intake difficult (45). Side effects have consistently been associated with decreased adherence and patients who experienced more than two aversive reactions were less likely to continue with their treatment. The literature on side effects clearly show that optimal adherence occurs with medications that remove symptoms, where as adherence is reduced by medications that produce side effects (46,47).

Dose adjusting by patients to suit their daily schedules has been documented to be a barrier to adherence. A common shift of a three times a day to a two times a day pattern has been identified in patients taking ART (40). Some studies found that patients who were on twice daily doses or less reported better adherence and were more likely to take their medications when away from home (48,49).

Other studies have shown that some patients avoided taking their medications at work due to short term side effects which other people might observe like nausea, feeling tired and sluggish (50).

The hustles and demands on medication regimens in form of number of pills that have to be taken, the size and taste of pills, the frequency of dosing and how the normalcy of daily life can "get in the way" and interfere with adherence (40,44).

Depression or negative mood states is a recurring factor associated with adherence in literature. The emotional trauma experienced when dealing with issues of chronicity and uncertainty associated with HIV/AIDS diagnosis and treatment plan has been identified to contribute to non adherence to ART (42,45,51).

2.5 SOCIO-ECONOMIC AND CULTURAL RELATED FACTORS

Fear of other people knowing or noticing patients taking ART or the effects of medications may lead to others guess about their illness. Patients instead, resort to taking their medications in secrecy or avoid situations exposing their status (42,52). Taking medications may 'out' infected individuals. Such concerns arise in different settings, particularly at work and other public environments. Even in the confines of one's own home, one's status could be inadvertently disclosed to others. As a result, many try to hide medications and adopt dosing schedules and routines to conceal their pill taking as well as their diagnosis from others, which can cause adherence stress (50). Disclosure of HIV status or HAART may result in antagonism from others who hold negative attitudes and beliefs about HAART, potentially impeding adherence (50). Stigma has been identified in literature as a factor hindering patient adherence to ART. Patients talk about the difficulties of taking medications in public because they do not want anyone to know about their status (53). In other studies, the cost of medication has been associated with lack of patient adherence, leading to extended drug holidays (37). Social supports for medication adherence plays a critical role in supporting patients adhere to their medications. Patients whose families offered no or erratic supports have difficulties in adhering to their medication schedules (36).

2.6 RESEARCH CHALLENGES

Assessing adherence poses numerous challenges. It is easy for health workers to miss adherence problems because patient self-reports of adherence tend to be exaggerated

(54,55) due perhaps both to a recall bias and a desire to please the provider and avoid criticism. In addition to misreporting of adherence by patients, estimates of adherence made by health care providers are also usually over optimistic (56). Adherence to HIV medications is an extremely complicated process that includes both the drugs themselves and the adjustments to daily life necessary to provide the pre-requisite conditions for effective drug therapy (46).

2.7 MEASURING ADHERENCE

Research on adherence has been hampered by the absence of a convenient means of measurement. Various objective methods are available, but each has significant practical limitations: their objectivity and sophistication rises in parallel with cost and difficulty in administration (57). The lack of a gold standard to measure adherence and the dynamic nature of medication taking behaviours further complicate adherence assessments and interventions and highlight the need for additional research in these areas (58).
Adherence to therapy is difficult to measure accurately. The most common methods used are pill counts, reviews of pharmacy records, self reporting and use of electronic medication monitoring devices.

Self reports

Patient self report represents a simple and relatively inexpensive way of measuring adherence, yet it often overestimates it. Frick and colleagues, for example, documented 88% adherence to ART via self report versus 66% via Medication Event Monitoring System (MEMS) (59). Similar findings have been reported by others, and overall, self reported adherence fails to identify 20% to 30% of non adherent patients (60). Self report assessments are mainly performed using non standardized questionnaires/surveys and include recall of adherence over a specific time frame (2-3 days, 7 days, 1 month). A 3 to 7 day recall has been shown to be more closely related with viral load suppression than longer periods of time (61). In research setting, the patient medication adherence questionnaire represents one of the most frequently used tools to assess self reported adherence (62).

Clinical reports

A number of studies have shown that Clinicians are poor estimators of adherence, yet national guidelines emphasize that they should use their estimate of treatment adherence when initiating ART in asymptomatic HIV infected persons (63,64). According to Helene Hardy, most clinicians in busy settings have to predict patient's adherence rather than thoroughly assess it. This might ultimately result in the withholding of ART from a patient estimated to adhere poorly to therapy and to be at risk for viral resistance. On the other hand, overestimation of adherence may be more common among clinicians who have increased familiarity with a patient and in whom they may limit efforts to detect new difficulties with adherence (58).

Pill counts

Pill count represents another method available to measure adherence to ART. It often overestimates adherence because of the well known problem of "medication dumping" (65,66). Pill counts are of limited use in clinical practice because they are time consuming, not well suited for a busy outpatient setting, computationally complex and often felt as an intrusion of privacy by the patients (58).

Pharmacy records

Review of pharmacy records can be used to measure adherence to therapy, particularly in settings where pharmacy records are entirely computerised (58). However, they do not provide evidence that the medication doses are taken appropriately and can sometimes lead to misinterpretation of usage when dosages change and/ or when patients receive ART during a stay in acute or long-term care facilities (67). Gaps in pharmacy refills are likely to indicate poor adherence to ART; however, it is more difficult to assume good adherence when timely pharmacy refills are present because receipt of the drug is not a guarantee that it was consumed (58).

Medication Event Monitoring System (MEMS)

MEMS are pill bottles with caps containing an electronic chip that records each time the bottle is open. The information is downloaded onto a computer and analysed to determine degrees of adherence and patterns of timing and pill consumption. MEMS have been extensively used in HIV adherence research and have been shown to provide adherence measures that closely correlate with viral suppression (49;68). MEMS provide an objective measure of pill bottle opening, pattern of adherence, accuracy of timing of doses, and a computerized way to measure adherence. Malfunction or loss of the electronic cap can occur and lead to irretrievable adherence assessments. However, the cost of MEMS is too prohibitive (58).

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CHAPTER 3: METHODOLOGY

3.1 METHODOLOGY AND APPROACH

It has been widely documented in literature that there is no single method or approach that can be said to be more important than others, as seen from the contextual relevance and application. Research literature has shown that the purpose of the study determines the methods that can be used for data collection (69,70).

The two research method categories have been stated as either quantitative or qualitative. Denzin and Lincoln (71), in explaining the difference between qualitative and quantitative researchers, explain that qualitative researchers stress the socially constructed nature of reality, the intimate relationship between the researcher and what is studied and the situational constraints that shape the inquiry- seeking answers to the questions that stress how social experience is created and given meaning, while in contrast, quantitative studies emphasize the measurement and analysis of casual relationships between variables, not process inquiry is purported to be within a value free framework (71). Creswell (72), explains that quantitative research focuses on the cause and effect of a phenomenon, uses measurements and observations, employs strategies of inquiry such as experiments and surveys and collects data on predetermined instruments that yield statistical data. Alternatively, qualitative research is one in which the inquirer makes knowledge claims based on multiple meanings of individual experiences, social meanings and historically constructed, with an intent of developing a theory or pattern. It is further stated that one of the chief reasons for conducting a qualitative study is exploratory. Exploring sensitive issues is better articulated through interaction that is found in qualitative inquiry. The lived experiences and meanings of peoples' lives are better explored through a qualitative study. Such an interaction offers an opportunity to capture the individual's point of view, examine their every day life constraints and securing of rich descriptive data. However, the concerns of a qualitative study, as assumed by various scholars include, among others, primarily with process rather than outcomes or products; more interest in meaning, researcher is the primary instrument for data collection and analysis; involves field work – observing and recording behaviour in natural settings; study is descriptive; process is inductive in that researcher builds abstractions, concepts, hypothesis and theories from detail. Qualitative methods are

useful for the study of human and social experience, communication, thoughts, meaning, attitude, and processes, especially related to the interactions, relations, development, interpretation, movement and activity of people (73). However, the insignificant size of the sample in qualitative studies cannot allow the generalization of the findings to get a representative picture.

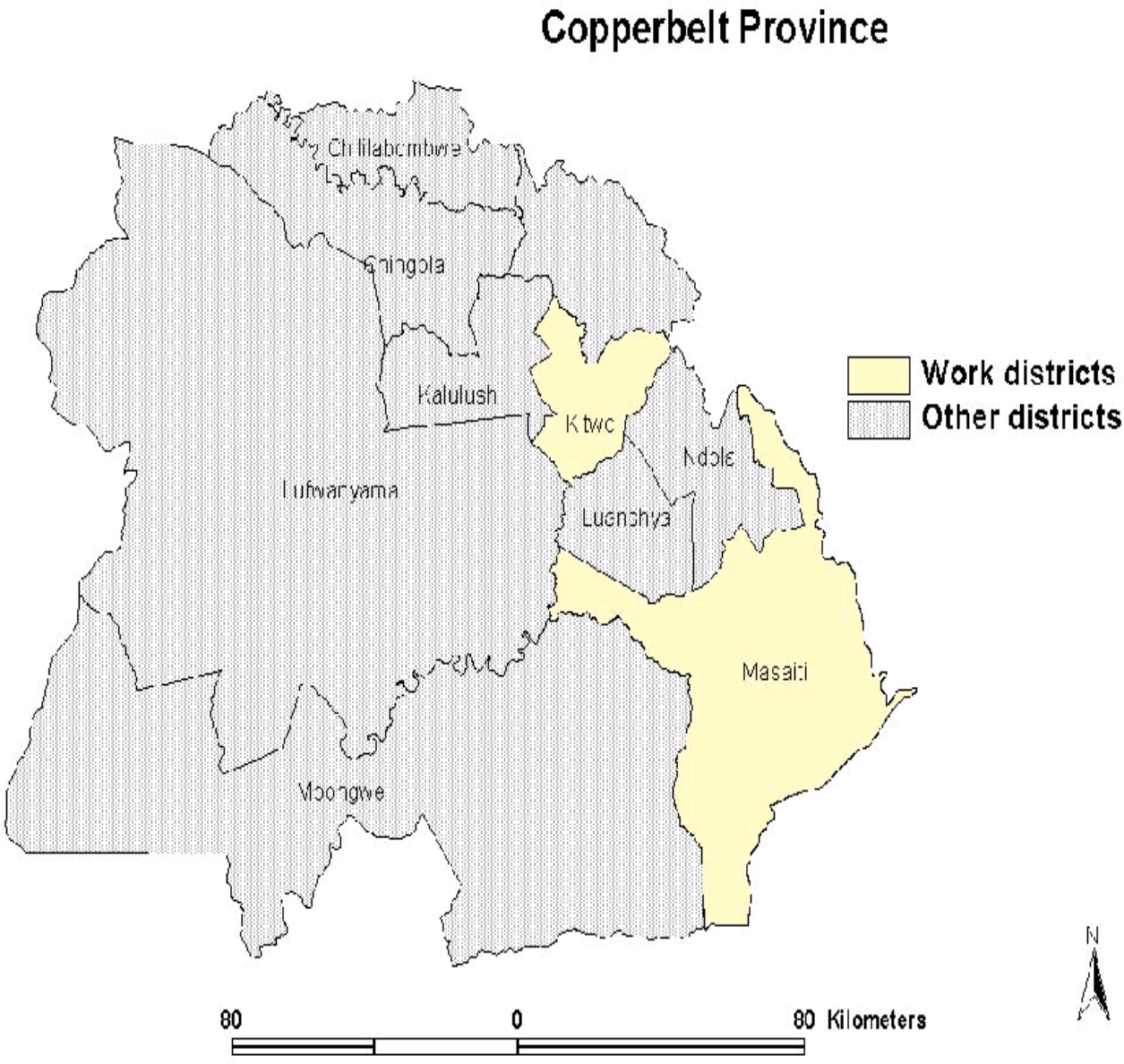
To investigate adherence to antiretroviral treatment in Zambia, I decided to undertake a qualitative research study. I chose a qualitative approach because the aim of the study was to gain an understanding of the holistic picture of factors surrounding adherence and non adherence to antiretroviral treatment among health care professionals and patients taking antiretroviral treatment and living in both urban and rural communities of Kitwe and Masaiti districts. Given the nature of this study, the use of in-depth interviews and focus group discussions (using interview guides with open – ended questions) with purposely selected participants was appropriate. In order to derive detailed information and useful insights, the depth and breath of investigating a phenomenon like that of lived experiences of patients taking ART, and the complexities of providing ART in resource limited settings would require the use of qualitative approach. Most studies examining factors associated with adherence have been conducted with quantitative surveys. Despite the multitude of studies conducted and the numerous factors identified, no single variable or combination of variables is sufficiently consistent to apply to any individual or group of people. Qualitative studies can enrich our understanding of the complex and multifactorial nature of the determinants of adherence and non adherence.

3.2 STUDY SETTING

The study was conducted in Zambia on the Copperbelt Province. The Copperbelt Province has one of the highest numbers of HIV/AIDS cases in the country, estimated at 22.1%. It also has a good number of patients accessing ART, estimated at 9,873 by the end of 2005 (12). The population of the Copperbelt is estimated to be around 1,581,221 people (74). Copper, which is the mainstay of the nation's economic activities, is produced on the Copperbelt Province. In Kitwe, data was collected from health facilities namely Chimwemwe Clinic, Ndeke Clinic and Kitwe Central Hospital. In Masaiti, data

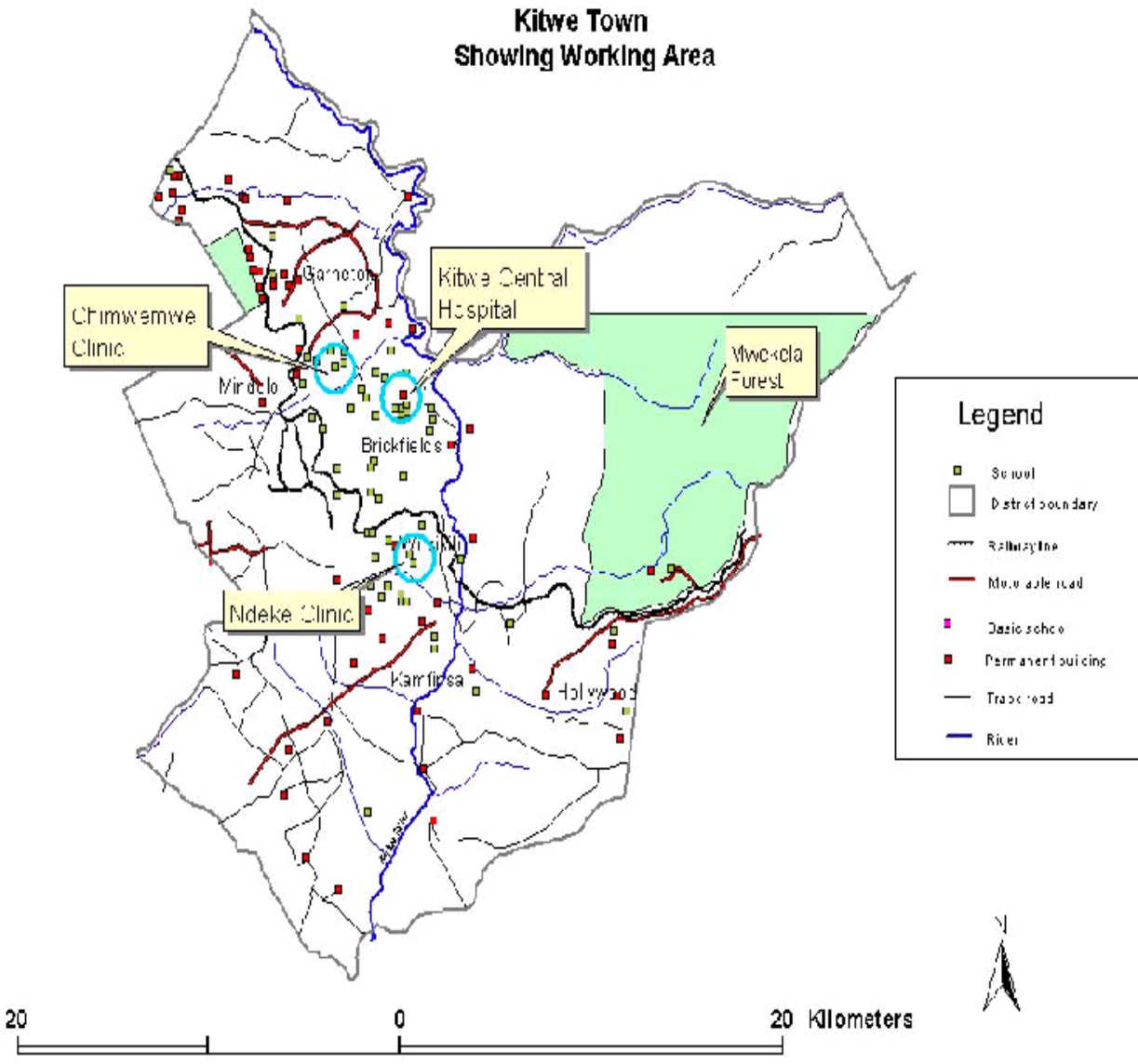
was collected from Fiwale Hills Mission Rural Health Centre and Mishikishi Mission Rural Health Centre.

Map of the Copperbelt Province



Source: Central Statistical Office, Lusaka (2006)

3.3 KITWE DISTRICT



Source: Central Statistical Office, Lusaka, 2006

Kitwe district is located on the Coperbelt Province of Zambia and covers a radius of 737 square kilometres. It shares boarders with Chingola on the north, Mufulira in the north-east, Luanshya in the south and Kalulushi in the west. It is the second largest city on the Copperbelt Province and third in the country. Kitwe has a tropical climate and vegetation with temperatures ranging from 18 - 36 degrees Celsius. Kitwe is located in the centre of the province.

According to the Census of population and Housing of 2000, Kitwe had an estimated population of 410,448, with a population density of 557 persons per square kilometre. The population growth rate for the district is 2.2%. The main economic activity in the district is copper mining, which employs about 51% of those in formal employment. The Government and Private sector employ the remaining 49% of those in formal employment (74). Kitwe is among the few towns in Zambia exhibiting economic growth after the privatisation era. A good percentage of the population are not engaged in meaningful economic activities. The prevalence of HIV in the district is 26.6% (6). The district has 19 Government run clinics and one public hospital. The district has two privately run hospitals, one by the mining company and the other one by some new investors. It also has 22 clinics and surgeries run by private institutions. There were four government institutions offering ART and a number of private ones at the time of this study. There were 4,317 patients accessing ART through the public health system at the same period. The district runs two parallel ART programmes, one being coordinated at the DHMT and the other at the district's tertiary government hospital at Kitwe Central Hospital. The district has over 75 doctors, over 400 nurses, and over 100 paramedical staff. The district has one training institution for Registered nurses and midwives. The district receives its drugs and laboratory supplies from the Medical Stores Limited, which is a government institution mandated to procure drugs and supplies on behalf of all government institutions. Tuberculosis which is an opportunistic infection in people suffering from AIDS is among the top three diseases causing high mortality to the population of Kitwe. About 60% of the population have access to safe drinking water while 54% of the population have access to modern sanitation facilities (75).

Chimwemwe Urban Health Centre

Chimwemwe Urban Health Centre is located in Chimwemwe township of Kitwe district. It is about 8 kilometres from the town centre and 1 kilometre off the road going to Chingola. The clinic caters for urban and peri-urban areas around the catchment zone. The clinic caters for a population of 43,489. The clinic offers both preventive and curative services to the community. The clinic refers its serious cases to Kitwe Central Hospital which is about 4.5 kilometres away from the centre. The clinic has 16 health workers consisting of nurses and paramedical staff. The clinic has no resident Medical Officer but has a visiting one on specific days. The health centre started offering ART in 2005 and had over 300 patients on the treatment register at the time of data collection (75). The health facility has a laboratory but it has no capacity to do specialized tests like the CD4 Cell Count and Liver Function test. Patients on ART are examined and treated by the Medical Officer and Clinical Officer. The health centre has 5 staff trained in ART and had 6 counsellors who all participated in the programme. Even those officers who had not yet been trained in ART also participated in the programme. The health centre conducted the ART clinic twice per week. Many people in Chimwemwe are self employed.

Ndeke Urban Health Centre

Ndeke urban clinic is located right in Ndeke township of Kitwe. It is about 10 kilometres from the town centre. The clinic caters for an urban population drawn from Ndeke Township and the surrounding compounds. Ndeke is located in the south-eastern part of the district. The catchment's population for the health centre is estimated at 41,684. The health centre offers both preventive and curative services to the community. The clinic refers its serious cases to Kitwe Central hospital which is 13.5 kilometres away from the health centre. The health centre has a total of 37 staff including nurses, paramedical and support staff. The health centre has no resident Medical Officer but visits the centre on specific days from the DHMT. The health centre started offering ART in 2005 and had over 250 patients on the treatment register at the time of data collection (75). The health facility does not offer specialized tests like CD4 count, Liver Function tests, and other highly specialized laboratory services. There were 3 Clinical Officers, 4 Nurses, 1

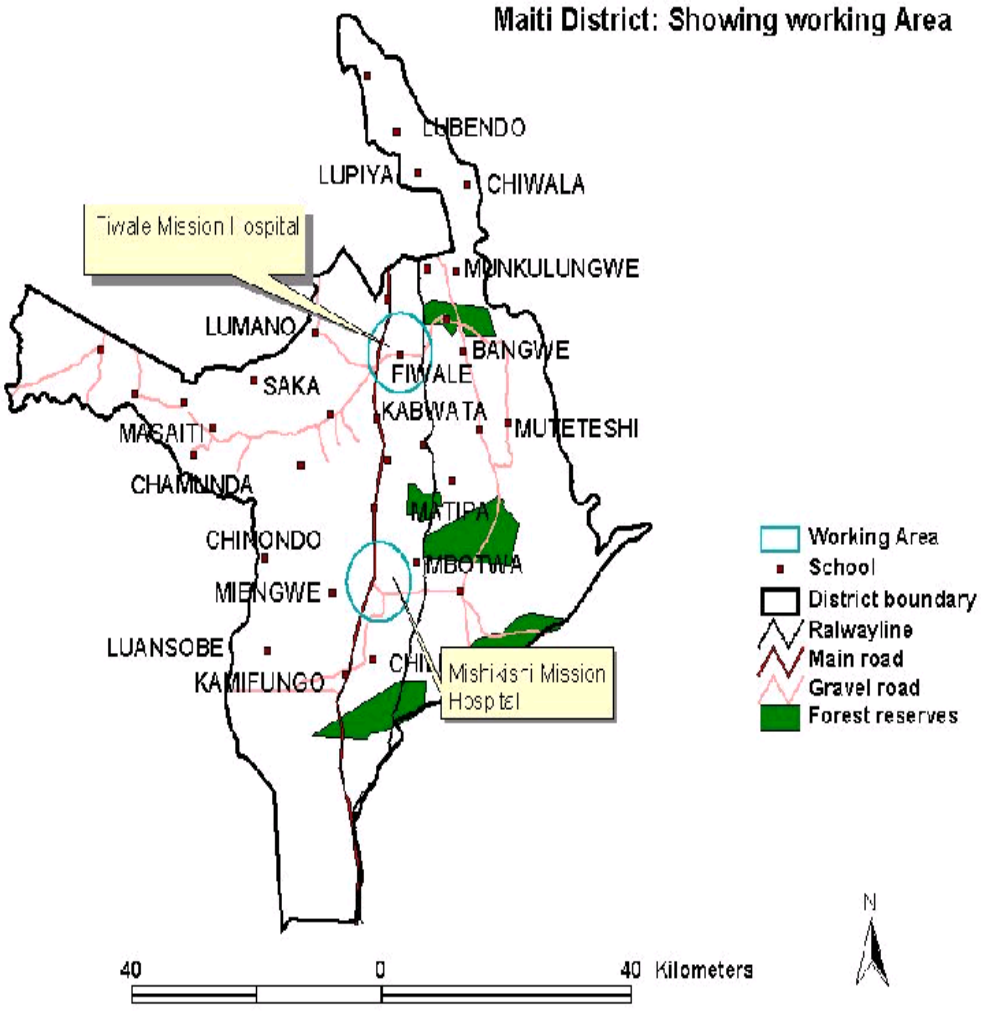
Laboratory Technician and a Dispenser involved in the ART programme. The health centre conducts ART clinics twice in a week.

Ndeke has a fair road network linking it with other parts of the district. Most of the people in communities serviced by the health centre are not in formal employment but are self employed.

Kitwe Central Hospital

Kitwe Central hospital is a third level regional referral hospital. It caters for the northern region covering Copperbelt, Luapula, Northern, and North-Western Provinces. The hospital provides specialized services in clinical disciplines including paediatrics, internal medicine, obstetrics and gynaecology, general surgery, radiology, specialized laboratory services including CD4 count, Liver function test and others. At a local level, the hospital draws its patients from all the townships in the district. The hospital is located in the north-western direction from the business centre and is about 3.5 kilometres away from the town centre. The hospital had 72 Medical Officers, 248 nurses, 11 Clinical Officers, 7 physiotherapists, 3 pharmacists and 8 pharmacy technicians, 11 Laboratory technicians, 1 Orthopaedic specialist, 13 radiographers, 9 Dental technicians, 2 nutritionists and 268 support staff at the time of data collection. Tuberculosis was the first ranked cause of death at the health facility, with malaria and pneumonia ranking in the second and third places. There were 3,630 patients accessing ART at the hospital at the time of data collection. The hospital had 120 health care staff trained in ART (76). The hospital conducts ART clinics on Mondays, Tuesdays, Thursdays and Fridays. The hospital attended to about 100 patients on ART every day of the clinic on average. ART was coordinated through two committees at the hospital, namely the Adherence Committee and the ART Committee. The ART Committee comprised all heads of departments while the Adherence Committee comprised those involved with the daily contact with patients like Medical Officers, Clinical Officers, Nurses, Counsellors and Pharmacists. The programme is coordinated by the Director of Clinical Services.

3.4 MASAITI DISTRICT



Source: Central Statistical Office, Lusaka, 2006

Masaiti is one of the rural districts of the Copperbelt Province. It shares boarders with six other districts namely; Mpongwe, Luanshya, Ndola, Mkushi, Kapirimposhi, Lufwanyama and the Democratic Republic of Congo. Masaiti has an estimated population of 113,900 people, with an annual growth rate of 2.6% The prevalence of HIV in Masaiti district is estimated at 11.3% (6). The district has 20 rural health centres scattered around the area.
The main ethnic groups are the Lamba people. The majority of the people earn their living through subsistence farming. Masaiti has been having a steady increase in the number of HIV cases over the past years. The increase has been attributed to high poverty levels in the district, increased trading activities with the bordering city and municipal towns, the busy highways passing through the district(Ndola-Kapirimposhi/ Mpongwe-Luanshya and Masangano-Luanshya) and traditional beliefs which still influence people's perceptions of the disease. The District Director of health coordinates all the health activities in the district. The district has no hospital. For hospital referrals, patients are sent to St Theresa Mission hospital in Mpongwe district or Ndola Central hospital and Arthur Davison Children's hospital in Ndola district. The district has one Medical officer who moves in all the 5 ART centres on specific days.

Fiwale Hills Mission Rural Health Centre

Fiwale Hills Mission Rural Health Centre lies 32 kilometres south of Ndola. Fiwale lies 5 kilometres east of Ndola-Kabwe highway. The centre covers an area of 600 square kilometres and is divided into 26 community neighbourhood health committees. The catchment's population is estimated at 18,000. HIV prevalence rates are on the increase because of its location and high levels of poverty (77). The majority of the people in Fiwale are generally peasant farmers. Fiwale Hills Mission Rural Health Centre provides both preventive and curative services to the community. The centre provides health services like children's clinics, family planning, antenatal care and HIV/AIDS/TB/STI care. The centre has about 100 patients on ART at the time of data collection. Fiwale started offering ART in 2005 (77). The ART programme is conducted twice in a week. The Medical Officer manages the patients. The centre does not have a resident Medical Officer or Clinical Officer. The health centre has a laboratory and pharmacy offering basic services. There were about 6 members of staff who were involved in the ART

programme. The centre gets it's consignment of drugs from the DHMT. The centre has two programmes of ART, one being a pilot project under CHAZ and the government one. The centre does not do CD4 count tests and relies on Total Lymphocyte Count and the Clinical picture of the patient to commence them on treatment.

Mishikishi Mission Rural Health Centre

Mishikishi Mission Rural Health Centre lies 50 kilometres south of Ndola and about 70 kilometres east of Kapirimposhi district in Central Province. The health centre is situated along the Ndola-Kapirimposhi highway. The catchment's population of the centre is about 10,000 people scattered around the area. It's social, economic and demographic characteristics are similar to those of Fiwale. It's location along the main busy road network connecting the Coperbelt Province and other parts of the country make the area prone to HIV infection. Mishikishi caters for six other rural health centres in the district in ART services (77). Most of these clinics lie about 20-30 kilometres away from the main centre. The mode of transport communication for the majority of the population is by walking, with a few using bicycles. The health centre did not have a Medical Officer or a Clinical Officer. The ART programme was conducted once per week on Fridays by a visiting Medical Officer who is based at Masaiti DHMT offices. There were about 8 health personnel at the health centre at the time of data collection. The centre has a laboratory and a dispensary offering basic services. The laboratory does not do CD4 count and other specialized tests. There were 5 health personnel trained in counselling at the centre (77). Patients are referred to Ndola for further investigations and management. There was only one nurse trained in ART at the time of data collection.

3.5 MY POSITION IN THE FIELD

The researcher undertook the study in a region he has lived and worked for the past 16 years. The researcher works for the Copperbelt University in the Health Services Department. The Copperbelt University Health Services provides primary health care services to the university community which comprise students, employees and their dependants. The department also provides health services to the nearby communities, especially in Child and maternal health, Tuberculosis and other general health services.

The Researcher has some experience in the management of chronic conditions like Tuberculosis and HIV/AIDS. The Researcher has also personal experience about the impact of HIV/AIDS at both family and community levels. During fieldwork, the researcher was identified by participants and gate keepers as a Researcher who had come to investigate adherence to antiretroviral treatment in the community. To avoid contradictions and suspicions, the researcher informed participants about his professional background. The Researcher and his assistants live in an environment and culture they were familiar with as that helped with communicating with the local people. The Researcher hails from a region which traditionally and culturally considered the study participants in Masaiti district as his "traditional cousins". This is an important cultural identification in an African context and helps in making people feel relaxed and open up. There was no evidence of respondents giving responses either to please the researchers or saying what they thought we wanted to hear. Most of the patients and health care professionals seemed to have enjoyed the discussions and spoke freely. Laughing among themselves was a common phenomenon during the discussions, especially when discussing topics related to sex. While the researcher was keen to understand how the participants constructed their social lives, there was at no time any intimate and regular contacts established with the members of the groups studied.

3.6 STUDY POPULATION

Recruitment of participants and pre-testing of instruments

Returning home in a capacity of a "Researcher", my initial task was to apply for ethical clearance. This was granted by the Tropical Diseases Research Centre Ethical Committee. Following ethical clearance, I started the process of identifying Gatekeepers in the community in which the study was going to be conducted, who will lead the network of contacts. With the help of a local Non Governmental Organization (NGO) called Copperbelt Health Education Project (CHEP), several potential research assistants were identified and interviewed for possible engagement. CHEP has a network of human resource working with Community based organizations in the two districts. Three research assistants were selected for the study. A training programme was arranged for

them in theoretical, ethical and methodological issues of the research topic and data collection methods. After the assistants were recruited, the interview guide for patients was translated into the local languages of Bemba and Lamba. All the research assistants were involved in the translation process being indigenous people. The guides consisted of themes in line with research objectives. Out of the three assistants, one was a female and she participated in Kitwe district. Some of the desired attributes of the assistants included good inter personal /communication skills, native of the area, fluent in the local language, mature, self motivated, college education and willing to work with minimum remuneration. The background of the assistants was retired Teacher, Pastor and Coordinator of a community based organisation working in the area of HIV/AIDS. I had to recruit two assistants for Masaiti district because of the vastness of the district. The instruments were pre tested in two health centres which were not part of the study sites in both districts. Two focus group discussions were conducted during the pre-test of instruments over a period of two days and appropriate adjustments were made to the interview guides. The District Health Directors in the two districts of study were approached and formal application letters were written to them requesting their institutions to participate in the study. The District Directors in turn also introduced the researcher and his team to the Officers who were directly in-charge of the antiretroviral treatment programmes. In most of these sites these turned out to be doctors, clinical officers and nurses. Orientation meetings were held with these health professionals in order to ensure that they understood the whole purpose of the study. Participants were recruited through the health care professionals for both in-depth interviews and Focus Group discussions. After the recruitment of potential participants, the researcher had to arrange a series of meetings with the potential participants to explain in detail the whole purpose of the study and offer the would be participants an opportunity to ask questions about the study.

Sample Selection

Maximum variation which is a strategy of purposive sampling was used to identify participants for the study. Selection of information rich participants was preferred in order to learn more about the issues of central importance to the study (78).

3.7 FOCUS GROUP DISCUSSIONS

Focus group discussions are group interviews with participants who are similar to each other in a way important to the researcher to provide qualitative data in a focused discussion to help understand the topic of interest. The nature of this homogeneity is determined by the purpose of the study. This similarity is the basis of recruitment, and participants are informed of these common factors at the beginning of the discussion. Focus groups comprise 5 – 10 people. The group must be small enough for everyone to have an opportunity to share insights and yet large enough to provide diversity of perceptions. According to Krueger and Casey (79), a focus group presents a more natural environment than that of an interview because participants are influencing and influenced by others, just as they are in life. The researcher serves several functions in the focus group discussion as a moderator, listener, observer and eventually analyst using an inductive process. Focus groups work particularly well to determine the perceptions, feelings, and thinking of the people about an issue. Focus group information can be used to design a large scale quantitative study. The intent of focus group is to promote self disclosure among participants.

Focus group discussions in Kitwe

In Kitwe district, the researcher held three focus group discussions. The composition of the three groups was one male, one female and a mixed group. The mixed group was well represented with equal number of both men and women. These were drawn from the two participating urban health centres. The ages of the participants were between 31 and 47 years, with an average age of 33 years. The group comprised people who were widows, widowers, married and single. The groups knew part of the participants whom they came together with from the same clinic. Most of the patients have been taking antiretroviral drugs for a period ranging from 5 months to 3 years. Most of the patients used to work before they became sick and at the time of the study, very few were engaged in gainful economic activities. However, the discussions were characterized by vigour to contribute as each participant wanted to share their own experiences. The groups exhibited openness throughout the discussions more so as seen from their differences in opinions about the subject matter. The third group which comprised both men and women was also drawn

from the same health centres. All the participating people were selected purposively by the health care professionals. The focus groups were held in the board room of CHEP's Training Centre following a discussion which was held with the participants to choose the venue. Participants were informed about the dates for the discussions a week in advance. However, follow up contact through phone was maintained. The first discussion did not take off as earlier planned as participants came late. But an hour later the discussion started. The discussions were held on three different days with each group featuring on a specific day agreed upon by both parties. The venue was quite relaxed and provided for confidentiality during the discussions. The movement of the participants was arranged in a way that they find their way to the meeting place and then they were reimbursed for the transport expense they incurred. The researcher and his assistants had to introduce themselves to the participants before the discussions. The researcher also clarified the purpose of the study and what will be done with the data. He also informed participants about how their confidentiality will be protected in the data at all times during discussion, analysis and even publication. Quick rounds of introductions were done among participants so that they could form the beginning of relationship with other participants. The discussions lasted between one and half hours to two hours. All the discussions were tape recorded and supplemented by hand written notes. Refreshments were also served to the participants during the period of the discussions. Before participating into the study, the participants were made to understand what they were consenting to and verbal consent was given to the research team. During focus group discussions, participants sat in a circle so as to allow the researcher have eye contact with the participants and be in a position to observe non verbal communication among the participants. Only members of the discussion group were allowed to be present in the venue of the discussions. All the members of the groups were given a chance to participate in the group discussions. This was done in order to ensure that no participant dominated the discussion at the expense of other participants' ideas or views. Ground rules were spelt out in order to foster freedom of discussion where everyone was free to express his or her opinions. Contribution during the discussions was as a way of raising a hand and each one was given a chance to talk. All the focus groups held in Kitwe were conducted in a local language known as Bemba and all the participants were fluent in the

language. Both the researcher and his assistant were fluent in the language. General introductions were done with the participants in order to make them feel relaxed before getting deep into the discussions. In these introductions participants mentioned where they stay, how long they have been on ART, distance from their home to the health centre, what they do for their living and their marital status. The role of the researcher and assistant in all these discussions was to ask questions to the participants, probe where there was need for follow up and listening to the unfolding lived experiences of the group. Before winding up the discussions, a recap of what had been discussed with the participant was done in order to ensure that the participants verified the information. At the end of each discussion, the researcher met with the assistant to review the day's discussions and made comments and observations. At the end of each day, the researcher took some time to listen to the tapes in order to hear if the recordings went well and to familiarise himself with the data. Data was entered the following day after each discussion by the research assistant.

Focus group discussions in Masaiti

A change in the initial research plan took place from Mpongwe to Masaiti following my securing a research grant from the Association of Heart and Lung patients of Norway (LHL). This was necessitated by the funding institution that was not operating in Mpongwe district. However, this did not affect the study objectives in anyway because the social and demographic characteristics of the two districts were the same. They are both rural districts having the same ethnic groups, living standards and economic activities. Following this development, an application to the Tropical Diseases Research Centre Ethical Committee was made for an amendment to the approved research protocol. Following the approval of the amendment, I approached the district Director of Health for introduction. The Director also introduced the research team to the Medical Officer in charge of the ART programme in the district. The Medical Officer was the one making contact with the health centres offering ART in the district. This was later approved and that was when the research team started collecting data from Masaiti district. In Masaiti, only two focus group discussions were conducted. However, the recruitment process was not short of difficulties. The initial attempt did not yield the

desired results as most of the potential participants failed to volunteer especially for the individual interviews. The explanations given by the health care professionals recruiting participants were that most of the potential participants expressed unwillingness to participate. Another issue that emerged from this interaction indicated that the political atmosphere which was obtaining at that particular time had an influence on their perception of the planned study. The potential participants claimed that they had been told by some politicians that some politicians were advocating withdrawing free ARVs when they came to power. This made the potential participants fear to express their views especially that they had not yet met the research team. Zambia was preparing for presidential, parliamentary and local government elections at the time of data collection. Therefore, initially the potential participants were not sure of the position of the researcher and his assistant until an orientation meeting was held with them to explain the purpose of the study.

At Fiwale Hills Mission Rural Health Centre, a focus group was conducted with men. There were 10 participants drawn from around Fiwale area. The discussion was held in a shelter provided for by the health centre. This was a shelter which the health care professionals used also for mother and child health activities like immunisation talks, nutritional demonstrations, and family planning and antenatal care talks with the mothers in the community. The venue was agreed upon by both the participants and the research team. The environment was quiet, relaxed and conducive for a discussion without distraction from outside. The centre also acted as a neutral venue as most of the participants had to cover quite some distance to reach the heath centre. The ages of the participants were between 27 and 45 with the average being at 36. The group comprised people who were widowers, married and single. The participants were also recruited through the health care professionals. Ground rules were also spelt out in order for the group have a free and conducive atmosphere for discussion. Contribution was by a way of raising a hand and each participant was given an opportunity to make their contributions. The discussion was tape recorded and as well supplemented by hand written notes. The duration of the focus group discussion took about 2 hours. At this FGD, the research assistants facilitated the discussion while the principal researcher observed the participants' group dynamics. The participants sat in a circle while they

were discussing and that allowed the researcher and his assistants to observe the group proceedings. The local language known as Lamba was used during the discussion. Participants were given transport re-imbursement to cover their local transportation. In total, they were given K25, 000.00 which translates to USD 5.00. Most of the participants spend about 4 hours to reach the health centre. At the end of the discussion, the research team had to go through what was discussed with the participants so as to verify the contents of the discussion. At the close of the meeting, participants were thanked for their efforts and were re-assured of confidentiality of the issues which they had discussed with the research team.

The other rural focus group was conducted at Mishikishi Mission Rural health centre with a group comprising men and women. The total number of participants was 10, including 5 men and 5 women drawn from around Mishikishi area. The discussion was held in a ward which the centre used for isolating infectious diseases. This venue was decided by both parties after consideration of the other option which was available. The other option was the shelter outside which according to the participants was too open for a sensitive discussion of that nature. The range of the participants' ages was between 29 and 47 years, with the average being 35 years. The venue was also viewed by the participants as being more central as most of the participants had to cover long distances to reach the health centre.

The group comprised participants who were widows, widowers, married and single. The participants were also recruited through the health care professionals. Ground rules were also spelt out in order for the group have a free and conducive atmosphere for discussion. Contribution was by a way of raising a hand and each participant was given an opportunity to make their contributions. The discussion was tape recorded and as well supplemented by hand written notes. The duration of the focus group discussion took about 2 hours. At this FGD, the research assistants facilitated the discussion while the principal researcher observed the participant group dynamics. The participants sat in a circle while they were discussing and that allowed the researcher and his assistants to observe the group proceedings. The local language called Lamba was used during the discussion. Participants were given transport re-imbursement amounting to K25, 000 (USD 5) to cover their local transportation. Most of the participants spend about 3 - 4

hours to reach the health centre. At the end of the discussion, the research team had to go through what was discussed with the participants so as to verify the contents of the discussion. Participants were thanked for their efforts and were re-assured of confidentiality of the issues which they had discussed with the research team.

3.8 IN-DEPTH INTERVIEWS

The purpose of a qualitative research interview is to obtain qualitative descriptions of the life world of the subject with respect to interpretation of their meaning using a semi structured guide. A guide has a sequence of themes to be covered, as well as suggested questions. Yet at the same time, there is openness to changes of sequence and forms of questions in order to follow up the answers given and the stories told by the subjects.
The research interview is an interpersonal situation, a conversation between two partners about a theme. It is a specific form of human interaction in which knowledge evolves through a dialogue. The qualitative research interview attempts to understand the world from the subjects' point of view, to unfold the meaning of people's experiences, to uncover their lived world prior to scientific explanations. The qualitative research interview is a construction site of knowledge (80).

In-depth interviews in Kitwe

In-depth interviews were used as the main method of collecting data. In order to get a holistic picture of this study, interviews made the researcher understand the world from the study informants' point of view. They told their life stories, their experiences and allowed the researcher to have a face to face conversation, which allowed for further questioning, probing and clarification of issues making the data collected rich and complete. All in- depth interviews with patients were held at Kitwe Central Hospital in Kitwe district. At the hospital, the Executive Director introduced the Researcher and his team to the Director of Clinical Services, who was in-charge of the ART programme. The Director clinical Services in turn introduced the Researcher to the Heads of out Patient Department (OPD) and Pharmacy for onward recruitment of staff participants. The participants included both men and women. The potential interviewees were met in their individual capacities for a briefing about the purpose of the study and thereafter, an

appropriate date was arranged with each participant. Participants were purposively selected by the health care professionals. Participants were drawn from different parts of the city. All the participants preferred the hospital venue for their interviews. They observed that the venue was most appropriate because there was no one who could become inquisitive or suspicious about their being at the hospital since they were patients who visited the hospital regularly. Individual written or verbal consent was obtained from each participant before the interview. The interviews were conducted in the adherence counselling room which was provided for this purpose by the hospital authorities. The office was located in the OPD and assured confidentiality. The office had two chairs and a table to be used by the researcher and the participant. In-depth interviews were conducted using semi structured interview guides for both patients and health care professionals. The interviews in most cases lasted about 60 minutes. All the interviews were tape recorded and supplemented by hand written notes. During in-depth interviews, both English and Bemba were used. The health care professionals preferred to be interviewed in English while most of the patients preferred the local Bemba language. At the end of the interview, each participant was thanked for their time and assured of confidentiality of the information shared. Before closing up the interview, a recap of what had been discussed with the participant was conducted in order to ensure that the participant verified the information. Each participant was given transport re-imbursement as a way of acknowledging their effort to the commitment and fulfilment of the interview obligation. At the end of each day, the researcher took some time to listen to the tapes in order to hear if the recordings went well and to familiarise himself with the data. Data was entered the following day after each discussion by the research assistant.

3.9 INCLUSION CRITERIA

- Men and women who have a confirmed HIV positive test result and were taking antiretroviral treatment.
- They should not be too ill to participate in the study.
- Aged between 20 – 49 years. For health care professionals the age was not very significant. However, gender proportions were taken into consideration.
- Participants should be members of the study community.

- Willing to volunteer to participate.

3.10 EXCLUSION CRITERIA

- Patients who were too ill to participate.
- HIV positive men and women who have not yet started taking antiretroviral treatment.
- Patients who were below 20 and above 49 years.
- Patients who had just started taking antiretroviral treatment at the time of the study.

3.11 DATA COLLECTION AND MANAGEMENT

For both group discussions and in-depth interviews, data was recorded using a tape recorder. Since focus groups were conducted by a facilitator and an observer, the observer also recorded the discussions manually. In order to overcome the problem of identifying individual speakers and the differentiation between statements of several speakers, participants were given numbers and the numbers were linked to the voices. A running order of the discussion was produced and involved listening to the taped discussions immediately after everybody left, in order to keep the voices of the participants alive in the researcher's mind. On the same day of the interview/discussion, a back up copy was produced from the original copy. Each tape was labelled with a number for easy identification. The labels included; date of interview, participant category and participant identity number. After interviews the tapes were handed to the research assistants for transcriptions. Although some discussions were done in a language the researcher does not speak fluently, care was taken to minimize losses of data that would arise from translations and transcriptions. An independent transcriber and translator was engaged to help strengthen the information collected. In order to carefully compare data collected from the two methods employed in the study, semi structured interviews with informants followed the same format used during group discussions with the same themes.

3.12 SECONDARY SOURCES OF DATA

Part of the information on government policies, guidelines on antiretroviral treatment and management was obtained from government documents. The maps depicting the study areas were obtained from the Central Statistical Office in Lusaka. They were digitalized using the Geographical Information System (GIS) from the census maps used during the 2001 tripartite election.

3.13 DATA ANALYSIS

Audiotapes of the interviews were transcribed in verbatim by the researcher and assistants and then translated from Bemba and Lamba local languages into English. The Researcher then read the transcripts independently and developed a coding frame for the analysis. The Researcher coded all the transcripts, and read independently the material. Material about participants' perceived factors influencing ART adherence and non adherence were identified and used for systematic condensation, according to the principles of Giorgi's phenomenological analysis (81) ,and modified by Malterud (73) . The analysis followed four steps: (i) reading all the material to obtain an overall impression and bracketing previous conceptions; (ii) identifying units of meaning representing different aspects of participants' perceived factors influencing ART adherence, and coding for these units; (iii) condensing and summarising the contents of each of the coded groups; (iv) generalising descriptions and concepts concerning perceived factors influencing adherence and non adherence to ART.

3.14 VALIDITY AND RELIABILITY OF DATA

Validity is another word for truth. It refers to the extent to which the data collection strategies and instruments measure what they purport to measure. Reliability refers to the extent to which studies can be replicated. This is the degree of consistency with which instances are assigned the same category by different observers or by the same observer on different occasions (82).

Efforts taken to strengthen and secure validity and reliability

During data collection, there were factors that could have posed threats to validity and reliability of this study. Measures that were taken to secure validity and reliability are explained below in relation to identified possible threats.

Pilot testing the interview guides

Since the interview guides were developed in Oslo, pilot testing was essential to check on the clarity of questions, questioning techniques during the interviews and establishment of rapport. Discussions on pilot testing interviews were carried out with the informants and colleagues in the research team who indicated that the interview guides were serving the intended purpose.

Interviewer as an instrument

Another factor that could have threatened validity and reliability of the study was the status of the interviewer as an instrument. The pilot testing helped the interviewers to improve their questioning techniques. Efforts were made to overcome the threat by practicing. Listening to the tapes after the pilot testing and also after each interview helped the researcher overcome possible biases. During the interviews, the researcher and his assistants listened carefully to the informants' answers and elaborations. The informants were given enough time to elaborate their answers with such remarks, 'Do you have anything else you want to tell me.' In addition, probes were used to obtain information. Consistency of information was checked by paraphrasing what the interviewees said, for instance, 'If I get you well, you said…'

Use of independent transcriber

To minimize on bias, after the interviewers transcribed and translated the interviews, an independent transcriber and translator went over the transcriptions thereby strengthening validity and reliability of data. The transcriber and translator listened to the interview tapes and compared with the transcribed interviews in order to identify possible misinterpretations. The interviewers considered suggestions made in the final transcripts.

Supplementary information

Another strategy used to strengthen validity and reliability was the use of different sources of information. Data collected from patients and health care professionals from both urban and rural settings was supplemented with data collected from key informants.

3.15 LIMITATIONS OF THE STUDY

Results from this study can not be generalized to the whole population of Zambia. The results can not also be generalized to the whole Copperbelt Province because the sample was small.

The study also relied solely on interview data.

3.16 ETHICAL APPROVAL AND CONSIDERATIONS

The project has been approved by the Regional Committee for Research in Norway and the Tropical Diseases Research Centre Ethical Committee in Zambia. Introductory letters were written to relevant institutions to participate in the study. The health care professionals approached the participants on behalf of the researcher. The objectives of the study were explained to all participants as well as the leaders of the bodies which represented the study subjects. Permission and informed consent was obtained without duress on the participants and participants had the right to withdraw from the study at any time. The Researcher asked for permission to tape record the focus group discussions and in-depth interviews so that it helped him capture accurately the participants' insights in their own words. Participants were informed that they could request the tape recorder to be turned off at anytime if they were not comfortable with it. Participants were also informed that their names would not be used at any point. They were also informed that if they did not wish to participate in the study that would not affect their ability to access the usual services they currently received or expected to get from their health providers then and in future. The expected interview time was also discussed with the participants. Participants were given an opportunity to ask questions about the study before they committed themselves to participate They were also informed about the possibility of having the final version of the findings of the study at all the institutions that participated

in the study like the Ministry of health ,the Network of Zambian People living with HIV/AIDS and that the results may also be used in further studies or as a contribution to the body of knowledge on adherence to antiretroviral treatment in Zambia.

The appropriateness of the language used to explain the purpose of the study and request for peoples' informed consent was done in a way understood by the participants at all the times, and clarifications made to ensure that their decisions were informed. The information given by the respondents was treated in the strict confidence and would be used for the furtherance of the study objectives only. The true identity of the respondents was always held in confidence. Sensitivity to age, gender and cultural context was considered during the study. Needy communities have high expectations when involved in a study. The researcher explained with the help of the representatives from each affiliated institution about the importance of the study and the benefits in terms of more knowledge on adherence to antiretroviral treatment in communities. There were no promises of money or other resources made to participants. However, the researcher considered modest budgets for drinks, snacks and transport re-imbursements. The researcher took responsibility for data protection, together with the assistants while in the field. An opportunity to verify the information given by the participants during the discussions was provided at the end of each discussion.

CHAPTER 4: SUBMITTED MANUSCRIPT

Perceived barriers and facilitators to patients' adherence to antiretroviral treatment in Zambia: a qualitative interview study

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Abstract

Background:

Adherence to antiretroviral therapy (ART) is important for effective treatment. Little is known about barriers and facilitators to ART in Zambia. The aim of this study was to explore patients' and health care professionals' perceived barriers and facilitators to adherence to ART in Zambia.

Methods:

We conducted a qualitative study in Kitwe and Masaiti districts in the Copperbelt Province of Zambia in 2006. We used a combination of in-depth individual interviews and focus groups with patients on ART, health care professionals working in ART clinics and other informants. The material was analysed using qualitative methods.

Results:

We identified barriers and facilitators which were diverse in nature and belonged to a wide spectrum of factors which include patient related, health service related, socio-economic and cultural factors. These include lack of communication and information about ART, inadequate time during consultations, follow up and counselling, forgetfulness, stigma, discrimination and disclosure of HIV status, lack of confidentiality in the treatment centres, lack of nutritional support, feeling better, prospects of living longer, family support, information about ART, support for income generating activities and transport..

Conclusion:

Our study suggests a multiplicity of factors and issues which need to be taken into consideration when providing ART. Further research is needed including participant observations to capture the actual interactions between patients and their health care providers. Also, future studies should assess the magnitude of non adherence to ART in Zambia using quantitative measures. Our findings can inform the design of interventions to promote adherence to ART.

Background

The term adherence has been defined as 'the extent to which a person's behaviour (in terms of taking medications, following diets, or executing life style changes) coincides with medical advice [1]. Antiretroviral medications have significantly improved the health and well being of many HIV patients [2]. Still, lack of strict adherence to highly active antiretroviral therapy (HAART) is considered to be one of the key challenges to AIDS care in the world. Estimates of average rates of non adherence to HAART range from 50% to 70%, and the risks associated with non adherence are extensive at both the individual and societal levels [3, 4]. Studies have found that adherence rates lower than 95% is associated with viral resistance to medications [5, 6]. While adherence to HIV therapy has been widely studied in resource rich settings, few studies have addressed adherence to HAART in resource constrained settings [7, 8]. Reviews of adherence to HIV/AIDS medication have mainly focused on a variety of factors which include characteristics of the medication regimen, social factors, psychological factors, patient-provider relationship, treatment regimen, disease and clinical setting [9, 10].

Zambia has a high prevalence of HIV infection. It is estimated that 16% of the adult population aged 15 – 49 years is infected and the deaths due to AIDS are estimated to 98,000 per year [11]. According to the Ministry of Health, the number of people accessing ART in the last few years has increased over eight fold from 3,000 in 2003 to over 47,771 by the end of 2005 [12]. HIV/AIDS treatment is given priority by the government [13-15]. In July 2005, the government started providing free treatment to people eligible for antiretroviral treatment (ART). This new policy includes free drugs and basic laboratory investigations [16]. However, a recent study conducted in one of the country's largest hospitals has raised concern about the emergence of resistant strain to the first line ART regimen in Zambia [17]. Little is known about perceived barriers and facilitators to ART adherence in Zambia.

The aim of this study was to explore patients' and health care professionals' views on barriers and facilitators to adherence to antiretroviral treatment in this country.

Methods

Data were collected during fieldwork in Kitwe and Masaiti districts in the Copperbelt Province of Zambia, from August to December 2006. Kitwe is an urban city whereas Masaiti is a rural town. We used focus group discussions and in-depth interviews with patients on ART, their health care providers and other people who were purposely selected on the basis of their experience with ART. Patients were recruited from five different health facilities: Three urban (Kitwe Central hospital, Chimwemwe and Ndeke Clinics) and two rural (Fiwale and Mishikishi health centres). Recruitment was done by health care professionals working in the ART clinics.

We recruited a sample of patients in their twenties or older with diverse social backgrounds and that had been taking medication for different lengths of time. We also recruited health care professionals who had experience with ART. Participants gave explicit verbal or written consent to participate in the study. All participants were informed that they could stop the interview at any point without stating any reason. Patients were informed that declining to participate in the study would not affect their access to treatment. Participants were given transport re-imbursement of US$ 5. The study was approved by the Regional Committee for Research in Norway and the Tropical Diseases Research Centre Ethical Committee of Ndola in Zambia.

Interviews

The first author conducted 22 in-depth interviews and three focus group discussions in Kitwe with the help of an assistant. Two focus group discussions in Masaiti district were conducted by two research assistants. Semi structured, face to face, tape recorded qualitative interviews, and lasting 60 minutes to 120 minutes were conducted by the first author and assistants. Of the 72 participants, 42 were interviewed in the hospital setting and 30 at a local Non Governmental Organisation's training centre. The sample size of 72 participants was a result of data saturation as consecutive interviews yielded diminished returns of new information.

We used interview guides for individual interviews and the focus group discussions. The interview guides touched on different aspects of perceived factors that influence adherence and non adherence to ART, including how participants perceived

HIV/AIDS and ART, their experiences about ART, information on ART, barriers and facilitating factors to ART adherence (see Additional file 1).

Analysis

Audiotapes of the interviews were transcribed in verbatim by the first author and assistants. The interviews were translated from Bemba and Lamba, which are local languages, into English. All authors read the transcripts from 10 interviews independently and developed a coding frame for the analysis. The first author coded all the transcripts, and all the authors read independently the material and contributed in negotiating the final categories and their contents. Material about participants' perceived barriers and facilitators to ART adherence were identified and used for systematic condensation, by applying the phenomenological method of analysis derived from Giorgi [18], and modified by Malterud [19]. The analysis followed four steps: (i) reading all the material to obtain an overall impression and bracketing previous conceptions; (ii) identifying units of meaning representing different aspects of participants' perceived barriers and facilitators to adherence, and coding for these units; (iii) condensing and summarising the contents of each of the coded groups; (iv) generalising descriptions and concepts concerning perceived barriers and facilitators to ART.

Results

We identified several factors that were being perceived as barriers and/or facilitators to adherence to ART. We have classified them in three categories: Health services related, patient-related, and socio-economic and cultural factors.

Health services related factors

We found that lack of communication about ART between health care professionals and patients and time constraints during consultations were perceived as barriers to adherence. Some patients said that they were not informed about how to take their medications by their health care providers when they started ART. Many patients mentioned the health facility as their most valuable source of information, but for many

patients the pharmacy was more important. A 34 year old female patient, widow and employed as a teacher explained her experiences:

"The doctor just writes prescription for collecting drugs. He does not discuss or give information on ART. There is no one who has asked me whether I'm taking my drugs or not; not even at the pharmacy." (Participant 7).

Lack of communication about treatment was also recognised by health care professionals as a potential barrier, as illustrated in this quote:

"Medicines are usually part of the pharmacy. Because of these changes in the doctors' routine work in the ART clinics, information dissemination to patients has not been so good. We encourage them to ask for more information at the pharmacy when they go to collect their medications." (Participant 10, 43 year old female health care professional).

Patients reported that health care providers rushed through their consultations, and as such they felt that the information given under such time-constraints could easily be misunderstood. Health care professionals on the other hand reported being overwhelmed with insufficient time to discuss in detail and assess patients' concerns and needs that might affect ART adherence. They observed that the ever increasing number of patients that accessed ART did not match with the number of health care professionals. Almost all the health facilities visited did not have a procedure of tracing and managing patients who had defaulted from their treatments. A 32 year old male health care professional shared his experiences:

"Like at this hospital, we have about 700 patients who have missed their scheduled monthly collection of drugs in the last three months. I do not know whether to declare them lost or not, but we don't know what has happened to them." (Participant 11).

Some health institutions had health care professionals who were not trained in counselling but who were involved directly in the ART programmes. The few that have

been trained lacked permanent places to conduct counselling. A 31 year old female health care professional said:

“We do not have a counselling room. So most of the time we use a small office we call an HIV/AIDS Office, but that office is being shared with the Accountant. So it means if I have to counsel a patient, that accountant has to leave her work.” (Participant 14).

Most patients and health care professionals from rural areas mentioned long distances from the treatment centres as a contributing factor to non adherence. They said that patients failed to walk long distances especially when they were too ill.

We found that nutritional support and good information about ART were experienced as facilitators to adherence. Nutritional support was mentioned by both patients and health care professionals as an important component of ART. Supply of nutritional supplements emerged as a facilitator for patients taking ART. A 27 year old female patient, single and unemployed said:

“I’m motivated to continue taking my drugs because of the food stuffs the Home Based Care Programme offers me. Since I’m not employed, I wouldn’t be managing to feed myself.” (Participant 2).

Some patients said that the information they received about ART motivated them to take their drugs. This could be information they had been given by health care professionals, or from booklets and workshops.

“More knowledge about ART that I receive from workshops motivates me to continue taking my drugs.” (Participant 19, 47 year old male patient, married and self employed).

Other facilitators to adherence that were mentioned by patients included free treatment and knowing health workers.

Patient related factors

Forgetfulness and experiencing better health were mentioned as barriers to adherence. Several patients mentioned that they forgot to take medication. Some patients forgot their medications because of their social lifestyles which interfered with the daily routines of taking medication, e.g. excessive alcohol consumption. Others forgot to take their medications as a result of pressure or busy work schedules. Some forgot because they were living alone, with no one to remind them to take their medication, especially when they were very ill. A 34 year old female patient, widow and employed as a teacher said:

"I take my medicines at 0600 hrs and 1800 hrs. Sometimes when I'm tired, I dream too much and then wake up later than 0600 hrs, and then I take my medicines like that. I just have that worry that maybe my immune system might go down, but that problem is with me." (Participant 7).

Excessive alcohol consumption was mentioned by both patients and health care professionals to be contributing to non-adherence. Beliefs about ART were also perceived by patients and health care professionals as barriers to taking the drugs. Some patients mentioned that ART was a sexual stimulant and that certain patients that did not wish to engage in sexual activities therefore decided to stop their treatment. Side effects were mentioned by several patients. Some health care professionals believed that side effects contributed to patients not adhering to their medications. A 27 year old female health worker said:

"I have this patient who is on the second line treatment who stopped her drugs as a result of side effects. She had terrible diarrhoea. She actually confessed that for her she had just to stop taking the drugs because the side effects were just unbearable, in the sense that she had this diarrhoea and she just didn't like it; but after so much counselling, I had to call in a doctor who talked to her, and we just had to stress to her that if she broke this rule now, it was very difficult for us to manage her. So she fortunately did continue and came back and said okay, the side effects are still subsiding but for now I'm okay."(Participant 12)

Some patients were reported to have stopped taking their medications because they were feeling better. Others who stopped taking their medications were said to be overwhelmed by 'pride', because they were looking physically fit and were back in their healthy, functional state. A 37 year old male patient, married and self employed said:

"There is this patient in my neighbourhood. He has stopped taking his medications after becoming well. He says that the drugs are too many to be taken everyday in the morning and evening as if it is a prayer." (Focus group interview 5, mixed group).

In contrast, experiencing better health was mentioned many times by both patients and health care professionals as a facilitating factor for patients to take their medications consistently. Most patients appreciated the benefits of ART in their lives and this encouraged them to continue treatment. A 43 year old female health care professional shared her experiences:

"I can give an example of one patient who was brought on a stretcher the first day he was seen by the doctor. Two weeks later, from the stretcher to a wheelchair, and he could stand from the wheelchair to sit on a chair to be seen by the doctor. A month later, that patient comes walking on his own. So what motivates them is what they get after starting the drugs." (Participant 10).

Health care professionals and patients observed that many patients were living longer than before due to ART. This was seen to motivate patients to continue taking their medicines. Many patients said that access to ART was an opportunity to prolong their lives, thus, enabling them continue with their caring responsibilities.

Some patients mentioned prayers as facilitators to adherence. Such patients believed that God was the most superior physician of their illness.

Socio-economic and cultural factors

Stigma, discrimination and disclosure of HIV status, and concerns about confidentiality were reported as barriers to adherence. Some patients and health care professionals mentioned that stigma was still high in their communities and families despite the positive benefits of ART. Some patients were reported to have withdrawn from social life as a result of being HIV positive. Disclosure of one's status and taking ART had negative consequences in many patients' lives. Most patients said that they could not disclose their status for fear of being victimised, rejected or accused of infidelity. Because of the traumatic nature of such experiences, some patients have ended up not adhering to their medications, as explained in this quote by a 27 year old female health care professional:

"I have one client who is HIV positive and has disclosed to her husband. The husband has been negative about it and it has been affecting her. She has been non compliant with her medications and she has been in and out of the hospital ward. We just have to keep on talking to her. Each time her relatives come in, they are pleading, can you please talk to our sister." (Participant 12).

Many patients expressed concerns about confidentiality in the treatment centres, especially in the pharmacies where they collected their medications. The affected patients felt unsafe or uncomfortable with accessing their medications at the pharmacies. A 35 year old female patient, married and a businesswoman explained:

"The current place they use to dispense ARVs is next to the main pharmacy and many people have come to know that. There is also a nutrition office on the other side. Some patients shun sitting on the bench and opt to go and stand somewhere else and wait for the people to finish before they can collect their drugs. I have seen this myself. This treatment has just come and people are not yet used to such." (Participant 8).

Some patients mentioned that they experienced difficulties in explaining their illnesses properly to their doctors because of poor confidentiality.

“We are seen in the same room with other general cases. Most of the times we are found in situations where you are two patients in the same room and that becomes very difficult to explain properly about your illness when there is a stranger.” (Participant 6, 33 year old female patient, married and a housewife)

The use of alternative treatments was perceived by patients and health care professionals as a barrier to ART adherence. They observed that patients stopped taking their ART and concentrated on traditional medicines or other spiritual rituals. Lack of food was perceived as a barrier to ART adherence.

Many patients interviewed believed that ART cannot be taken without food. Despite being regarded by many as an important barrier to adherence, several patients and health care professionals mentioned self disclosure as a critical facilitator, usually linked to the support they received from their families. A 47 year old male patient, married and self employed shared his experiences:

“I have disclosed my status to my wife and children. They have accepted my situation and are very supportive. Even when I’m busy with work, they remind me to take the medicines.” (Focus group 1, male group).

Some patients and health care professionals stated that certain patients who belonged to support groups which had income generating activities were motivated to continue with their medicines because of the support they received from such groups. A 38 year old male patient, married and a peasant farmer said:

“Our support group runs a grocery and a hammer mill. Part of the money we generate assists us to support ourselves. This has motivated many of us to continue with our treatments.” (Focus group 4, male group).

Some patients who were registered and supported by NGOs mentioned the transport support they received each time they went for their medical reviews as a facilitator for their adherence to treatment.

Discussion

Validity and transferability

We have explored perceived barriers and facilitators to ART in a sample of patients, health care professionals, and other informants. We think our results may be valid and transferable to other settings in Zambia, though we can not determine to what extent different factors are barriers or facilitators in a given context. A strength of this study is that the results can however be used to understand the many different factors that may influence adherence to ART. We recruited participants from the ART clinics and were all taking medication or providing a service in the ART clinic. Interview guides were pre-tested in order to check for clarity of questions, questioning techniques and establishment of rapport. The interviewees were given enough time to elaborate their answers and consistency of information was checked by paraphrasing what the interviewees said. To minimize bias, after the interviewers transcribed and translated the interviews, an independent transcriber and translator went through the transcriptions as an effort to strengthen the data by independently listening to the interview tapes and compare with the transcribed interviews for possible misinterpretations. The interviewers considered suggestions made in the final transcripts. Another strategy used to strengthen the data was the use of different sources of information. Data collected from patients and health care professionals from both urban and rural was supplemented by data collected from other informants.

This study provides an overview of perceived barriers and facilitators to antiretroviral therapy in Zambia. Our study found barriers and facilitators which were diverse in nature and belonged to a wide spectrum of factors which include patient related, health service related, socio-economic and cultural factors. These include lack of communication and information about ART, inadequate time during consultations, follow up and counselling, forgetfulness, stigma, discrimination and disclosure of HIV status, lack of confidentiality in the treatment centres, lack of nutritional support, feeling better, prospects of living longer, family support, information about ART, support for income generating activities and transport.

Improved health as an ambiguous factor

One striking result was that of feeling better, which could be a barrier as well as a facilitator to ART adherence. Patients were reported to stop taking their medications when they felt better. On the other hand, patients and health care professionals mentioned that patients were motivated to continue taking their medications because of feeling better as a result of ART. Improvement of subjective health has to be understood in the context of patients' beliefs about the treatment and how well informed they are. Some patients believed that they were healed and therefore could not understand why they should continue taking medication. While a number of patients and health care professionals said that adherence counselling to patients was offered at the start of their treatment, the emerging scenario suggests a new approach to counselling. The stage of treatment when the patient is feeling better can be a critical turning point for patient adherence. Thus, it seems logical that adherence counselling should focus in particular on patients during this phase of treatment. Also earlier studies have reported feeling better as either a barrier or facilitator to adherence [20, 21].

Communication and information about medication

Lack of communication and information about ART emerged as a barrier to adherence in our study. Most patients and some health care professionals mentioned that patients received little or no information about their medications from their health care providers. Other studies have also found that poor or lack of communication was a barrier to adherence to ART [22]. Most patients also mentioned their health facilities as their major source of information about their treatments. In the hospital-setting patients and some health care professionals stated that such information was provided at the pharmacies and not during consultations with doctors. Patient-provider communication has been shown to potentially facilitate adherence. Patients who receive adequate information about their treatment regimens were more likely than others to comply with medical advice [23, 24].

Confidentiality

Another issue that emerged from the study was that of confidentiality in the treatment centres especially at the pharmacies. While the pharmacies were used as information

dissemination centres for ART adherence, most patients did not favour that approach. In some health facilities, the pharmacy for dispensing ART was different from the general pharmacy, which made patients feel labelled by their health institutions. This illustrates the importance of taking confidentiality and stigma issues into consideration when the provision of ART is being scaled up.

Stigma

Some patients and health care professionals mentioned that stigma was still rife in their families and communities. Stigma has been highlighted in other studies as a barrier to ART adherence [25, 26] and it has been demonstrated that fear of disclosure of HIV/AIDS status or being noticed taking medication can contribute to patients not adhering to their medications[27, 28]. However, while disclosing one's HIV status was mentioned as a barrier by some patients in our study, for others, disclosure was said to facilitate adherence to ART. They were motivated to continue taking their medications because of the strong support they received from their spouses, families and communities.

Nutritional support

Nutritional support emerged as a critical factor for ART adherence. Lack of food was mentioned by both patients and health care professionals as a contributing factor to non adherence to ART while nutritional support was mentioned as a facilitator. However, most of the health facilities did not provide any nutritional support to their patients on ART. Lack of food has been identified before in some studies as a factor responsible for patients defaulting from their treatments [29].

Conclusion

In this study we have identified the multiplicity of factors and issues that need to be taken into consideration when providing ART. Further research is needed, including participant observations, to capture the actual interactions between patients and their health care providers. Also, future studies should assess the magnitude of non adherence to ART in

Zambia using quantitative measures. Our findings can inform the design of interventions to promote adherence to ART. However, the complexity of factors acting as barriers and/or facilitators to treatment adherence imply that the effectiveness of such interventions are unpredictable and need to be evaluated rigorously, preferably in randomised controlled trials.

Competing interests

The authors declare no competing interest.

Authors' contributions

Nawa Sanjobo (NS) was the principal investigator of the study. NS was responsible for the conception. NS, Jan C. Frich (JCF), Atle Fretheim (AF) all contributed to the design of the study. NS was in charge of fieldwork. NS, JCF and AF contributed to literature review, analysis and writing of the article. All authors read and approved the submitted version of the manuscript.

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Tables

Table 1. Characteristics of participants (n = 72)	
Characteristic	**No.**
Patients	**60**
Age, years	
20 – 29	17
30 – 39	33
40 – 49	10
Gender	
Men	33
Women	27
Urban Participants	40
Rural Participants	20
Taking ART 0 – 12 months	37
Taking ART over 12 months	23
Occupation	
Professionals	2
Self - employed	30
Unemployed	28
Marital status	
Married	20
Single	12
Widowed	28
Education	
0 – 7 Grades	30
8 – 12 Grades	25
College/University Level	5
Health care professionals	**12**

Age, years	
20 – 29	2
30 – 39	7
40 – 49	3
Gender	
Men	4
Women	8

Table 2. List of barriers and facilitators to adherence to antiretroviral treatment

	Barrier	Facilitator
Health service related	Lack of communication about treatment	Nutritional support
	Time constraint	Knowing health care professionals
	Language barrier	Information about ART
	Lack of information about ART	Government policy of free ART
	Poor staff competences	
	Lack of patient follow up	
	Inadequate counselling	
	Long distance to treatment centres	
	Lack of confidentiality	
Patient related	Side effects	Feeling better
	Pill burden	Prospects of living longer
	Beliefs about ART	Prayers
	Forgetfulness	
	Excessive alcohol consumption	
	Feeling better	
Socio-economic and cultural	Lack of emotional/psychological support	Family support
	Lack of food	Support programmes for income generating activities
	Lack of disclosure of status	Disclosure of status
	Stigma and discrimination	Free transport
	Preference of alternative treatments	

CHAPTER 5: RECOMMENDATIONS

This study has explored factors that influence adherence to ART in a sample of patients, health care professionals and other informants and I think the results may be valid and transferable to other settings in Zambia, though I cannot determine to what extent different factors influence adherence to ART in a given context. A strength of this study is that the results can however be used to understand the many different factors that may influence adherence to ART.

There is need for intervention and quantitative studies in future in this setting, and I so far suggest some recommendations:

1. Recommendations to Government and policy makers

I) My study found that patients had trouble with understanding information material and that available material was often written in English only. For some patients language was a barrier. I therefore recommend that the Ministry of health take measures to improve health education materials, both in English and local language, aimed at patients diagnosed with HIV and AIDS.

II) Participants in this study reported that most health facilities lacked room for activities such as counselling, consultations, laboratory and dispensing. Health care professionals reported this as a barrier to adherence. I therefore recommend that the Ministry of health advocates investment in infrastructure development in order to meet the demands of scaling up ART services.

III) This study suggests that if patients have to take large quantities of drugs each day, this may be a barrier to adherence to ART. In order to improve adherence, i suggest that the Ministry of health should advocate government to lobby donors to help purchase fixed dose combinations of ART.

IV) In this study, it was found that nutrition support was perceived as a facilitating factor to ART adherence, while lack of food was perceived as a barrier to ART adherence. I

therefore suggest that the Ministry of health and NGOs should advocate government to introduce a policy that incorporates nutrition in the treatment package.

V) This study found that long distances from health facilities were reported as a barrier to adherence, especially in the rural areas. It is therefore suggested that government should increase the number of sites offering ART as a way of working towards achieving the vision of the health reforms of bringing health services as close to the family as possible.

2. Recommendations to the health care system (Implementing institutions)

I) Lack of competence in staff was perceived as a barrier to ART adherence by both patients and health care professionals. This would suggest the need to train health care professionals in counselling and ART management.

II) Availability of information and education materials was perceived as a facilitator to ART by patients and other people interviewed. This therefore suggests that the health facilities should provide such materials to patients and their supporters regularly. These materials could be much more helpful if they were available in local languages.

III) My study found that patient-provider interaction and information giving was almost non existent. Lack of communication was perceived by patients and some health care professionals as a barrier to ART adherence, while some patients mentioned knowing health care professionals as a facilitating factor to ART adherence. This suggests that patient education and counselling should be improved or encouraged.

IV) Lack of confidentiality at treatment centres was perceived by patients as a barrier to ART adherence. It therefore appears that improving working environment in health care settings may ensure confidentiality during consultations, waiting times and when collecting medicines at the pharmacies.

V) This study found that most health facilities did not have patient monitoring and follow up system. That led to some health facilities losing considerable numbers of patients. I therefore recommend that health facilities should establish patient monitoring and follow up systems.

VI) Collaboration between health care systems and other stakeholders supporting ART programmes was found not to be well streamlined. Good collaboration has potential to foster patient tracking and follow up. I therefore recommend defined collaboration among all stakeholders in the ART programme.

VII) Stigma was still rife in families and communities, and i also found that some health facilities had separate dispensing outlets or pharmacies for ART. Stigma was perceived to be a barrier to ART adherence, and i therefore suggest that ART services should be integrated into the general health services as this may reduce stigma and increase the uptake of ART services.

3. Recommendations to patients and the community

I) This study found that lack of human resources was perceived as a barrier to ART adherence programmes. This therefore appeals for consideration to train community lay people in counselling so that they may help with patient support in the communities.

II) In this study, i found that stigma was still high in families and communities. HIV/AIDS and ART education campaigns may reduce stigma in communities and may also lead to decreased discrimination of individuals with HIV/AIDS and ART.

III) Family and community support emerged as a facilitating factor to ART adherence in this study. I therefore suggest that families and communities should be encouraged to form support groups focussed on ART to help with adherence strategies of coping with chronic illnesses.

IV) This study found that patients feared to disclose their HIV-status to their spouses, families, friends and communities for fear of rejection and victimization. This suggests that empowering patients with skills in disclosure counselling may help them in negotiating their life situations in their relationships, families and communities.

V) Income generating activities were perceived as a facilitator to ART adherence and lack of food and other nutritional supplements was perceived as a barrier to ART adherence. This suggests that supporting patients engage in income generating activities may promote adherence to ART.

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Appendices

Appendix 1: In-depth Interview Guide for ART Patients

Interview no ---------- Location ----------

Introduction: All the interviews will start with thanking the participant for participating in the study**.** Explain the purpose of the interview, make the respondent relaxed, assure confidentiality of information they provide and thank them for their time. Make them feel that the information they are going to provide is important for the furtherance of the study objectives. Show the participant the information letter or read it to them if they are illiterate. Both the participant and the researcher should sign the informed consent form, or oral consent is given on a tape recorder if the respondent is illiterate. In the case where a translator is used, explain to the participant the role of the translator and the role of the researcher. Ask the participant for their approval to use a tape recorder to record the interview and/ or for taking notes throughout the interview.

1. Socio – Demographic Information

a) How old are you?

b) How long have you been living around here? (Where did you live before?)

c) Do you have any education?

d) What do you do or have done for your living?

e) Are you married?

f) Do you have children?

g) What is the distance from where you live to the clinic?

2. Service Factors

a) Please tell me more about your experiences with finding help to receive ART at your health facility

Probe for:

- Handiness of the health facility to meeting the ART needs of patients
- Relationship between health workers and patients
- Availability of drugs
- Availability of health workers

- Infrastructure availability

3. Knowledge, Perceptions and Beliefs about HIV/AIDS and ART

a) Please tell me more about HIV/AIDS and ART

Probe for:

- Difference between HIV and AIDS
- When to start treatment
- Difference between CD4 count and Viral load
- Relationship between adherence and viral load
- Type of medication being taken
- Knowledge about side effects of drugs
- Duration of taking medication

a) In your opinion, are there any beliefs that you feel may influence the pattern of your taking ART?
b) (Re-assure the patient of confidentiality) Tell me more about what you know about being on ART and your sexual life.
c) Tell me too about what you know about being on Art and taking alcohol
d) From your experience, how do people handle issues of disclosing their status of taking ARVs to their partners?
e)

4. Information on ART and Adherence

a) Where have you received information about how to use your medication?
b) Has anyone told you or have you read what may happen if you do not take your medication according to the health professionals' instructions?
c) How has the information you have received about ART affected your life on ART?
d) In your opinion, what do you think should be done to improve the level of ART adherence?
e) How would you describe the information offered by health workers in the ART Programme to patient's lifelong needs of adherence?

5. Barriers and Motivating factors to adherence to ART

a) According to your experience, do you know any patients who do not take their medications as prescribed and why?

b) In your opinion, why may patients not come back for their monthly visits?

c) What do you think can motivate patients to come back for their monthly visits?

d) What sort of assistance do you receive from health workers to help you manage ART?

e) What could be improved in the health facility you use?

NB. Thank the participants for their efforts and contributions during the interviews. Do a recap of what was discussed with the participants so that they can verify the information. Assure them again of confidentiality of the information they have shared

Appendix 2: In-depth Interview Guide for Health Care Professionals

Interview no --------- Location ----------

Introduction: All the interviews will start by thanking the person for participating in the study. Explain the purpose of the interview, make the respondent relaxed, assure confidentiality of information they provide and thank them for their time. Make them feel that the information they are going to provide is important for the furtherance of the study objectives. Show the participant the information letter. Both the participant and the researcher should sign the informed consent form. Ask the participant for their approval to tape record the interview or taking notes throughout the interview.

1. Socio – Demographic Information

a) How old are you?

b) How long have you been working around here?

c) What is your occupation?

d) What is your education?

e) Are you married?

2. Service Factors

f) Tell me more about how ART programme is coordinated at your health facility:

Probe for:

- Staffing levels and responsibilities
- Infrastructure
- Handiness of the facility to meet the needs of ART patients
- Motivation

3. Knowledge, Perception and Beliefs about ART.

a) Please tell me more about ART:

Probe for:

- National policy on ART
- Current treatment guidelines
- Availability of adherence policy or guidelines

- Concept of adherence

b) What do you know about ART?

c) How does it work around here?

d) How do people deal with HIV/AIDS in this area?

4. Information on ART and Adherence

a) How do you tell ART patients how they should use their medication and do you tell them what might happen if they do not follow instructions?

b) What do you tell patients about how they should use their medications?

c) Do you have any written patient information?

d) In your opinion, what do you think should be done to improve the level of adherence to ART among the patients?

5. Barriers and motivating factors to adherence to ART

a) According to your experience, do you know any patient(s) who do not take their medications as prescribed and why?

b) Do some patients not turn up for their monthly visits? What do you think are possible reasons for this?

c) What do you think motivates patients to take their medications as prescribed in this setting?

d) What are the barriers to patients taking their medications as prescribed, from your experience?

e) How do you address the treatment plan for patients who do not take their medications as prescribed at your health facility?

NB. Thank the participants for their efforts and contributions during the interviews. Do a recap of what was discussed with the participants so that they can verify the information. Assure them again of confidentiality of the information they have shared.

Appendix 3: Agreement Form for Research Assistants

I ……..pledge that I understand the purpose of this study and that I will never use the information gathered through this study for my own interests or breach the confidentiality of any of the participants who will take part in this study at any time without the knowledge of the Principal Investigator.

……. ……..
Signature of Research Assistant Date

…… ……..
Signature of Witness Date

……. ……
Signature of the Investigator Date

Appendix 4: Participant Information Sheet and Consent Form

Iam a student from the University of Oslo in Norway studying International Community Health. Iam interested in issues that may help improve adherence to antiretroviral treatment in Zambia, with a six month fieldwork in Zambia from July until December, 2006. The aim of this study is to gain knowledge about adherence to antiretroviral treatment in Zambia, in order to identify interventions that may be efficient in increasing patient's adherence to antiretroviral treatment.

Iam interested in what you know and your experiences with antiretroviral treatment. I will conduct an interview with you about this. I will ask for your permission to tape record the interview so that it helps me capture accurately your insights in your own words. The tapes will only be heard by me alone for the purposes of this study. You may ask the tape recorder to be turned off at anytime. The information you provide will be treated confidentially and shall not be used for any other purpose other than the production of the report. Your name will not be used at any point.

If you do not wish to participate in the study, this will not affect your ability to access the usual services you currently receive or expect to get from your health provider now and in future. The interview is expected to take about 45 minutes. For those who participate in group discussions, the expected time is one hour and thirty minutes. Any questions you have about this study can be directed at the researcher (see contact details below). A summary of preliminary results can be provided at your request. The final results of the study will be shared with the Ministry of health, Network of Zambian People Living with HIV/AIDS, Non Governmental Organizations and Community Based Organizations represented in the study. The results may also be used in further studies or as a contribution to the body of knowledge on factors affecting adherence to antiretroviral treatment in Zambia.

Thank you for considering participating in this study.

Principal Researcher

Nawa Sanjobo

Department of General Practice and Community Medicine

University of Oslo

Norway

nawa.sanjobo@studmed.uio.no

Supervisor

Jan C. Frich

Department of General Practice and Community Medicine

University of Oslo

Norway

j.c.d.frich@medisin.uio.no

Co – Supervisor

Atle Fretheim

Norwegian Knowledge Centre in the Health Services

Oslo

Norway

atle.fretheim@kunnskapssenteret.no

Consent (Statement of declaration):

I understand the purpose of this study and have accepted to participate from my own accord, without being forced to do so.

Signed ---------- Date ----------

Witnessed by:

---------- Date ----------

Appendix 5: Ethical clearance from Norway

UNIVERSITY OF OSLO
FACULTY OF MEDICINE

To the relevant authorities

Institute of General Practice and Community Medicine
Section for International Health
P.O. Box 1130 Blindern
NO-0318 Oslo

Telephone: + 47 228 50 640
Telefax: + 47 228 50 607
E-mail:g.a.bjune@samfunnsmed.uio.no
URL: www.med.uio.no/ism/inthel

Date: July 4th 2006
Your ref.:
Our ref.:

Ethical Review

Investigator's name: Sanjobo Nawa

Title of the project: Factors affecting adherence to antiretroviral treatment in Zambia: A qualitative study of patients and health care professionals in Kitwe and Mpongwe districts

Due to a re-organization in the Norwegian system for ethical review of research students' projects involving a second country, the project proposal has not been subject to a national review process this year.

The students have filled in the ordinary national form for ethical review of research projects involving human subjects and supplied the protocol for their project. A group of experts (medical research ethics, medical anthropology and clinical medicine) in our department have read the applications carefully and made their comments. The investigator's project is found to abide to international regulations, and the comments (below) are to guide the investigators to clarify, elaborate or modify some point(s) before they apply to their national authorities. In case there are such comments in this letter, the investigator's application will be corrected accordingly.

Comments of the reviewers: This project is found to abide to international regulations and standards for ethical clearance considerations. The reviewers wishes the investigator good luck with his study.

Yours sincerely,

Institute of General Practice
and Community Medicine
P.O.Box 1130 Blindern
N-0318 OSLO, NORWAY

Gunnar Bjune,
Professor International Health
Head of M.Phil. education in International Community Health

Appendix 6: Initial clearance letter from TDRC

TROPICAL DISEASES
Tel/Fax 612837

RESEARCH CENTRE
P O Box 71769
NDOLA, ZAMBIA

TDRC ETHICAL REVIEW COMMITTEE
IRB REGISTRATION NUMBER: 00002911
FWA NUMBER: 00003729

TDRC/ERC/09/06

25th July 2006

Mr. Sanjobo Naawa
Principal Investigator
Factors affecting adherence to antiretroviral treatment in Zambia:
A qualitative study of patients and health care professionals in
Kitwe and Mpongwe districts
Kitwe

Dear Mr. Sanjobo Naawa,

RE: Factors affecting adherence to antiretroviral treatment in Zambia: A qualitative study of patients and health care professionals in Kitwe and Mpongwe districts

On behalf of the Chairman of the Tropical Diseases Research Centre Ethical Review Committee, I am pleased to inform you that at the committee reviewed the protocol entitled **"Factors affecting adherence to antiretroviral treatment in Zambia: A qualitative study of patients and health care professionals in Kitwe and Mpongwe districts."**

I wish to inform you that the TDRC Ethical Review Committee approved the protocol for the study.

The study has been accepted as adhering to the Ethics Standards for Epidemiological research. This letter certifies that all conditions were met to the satisfaction of the committee and constitutes the Ethics approval.

This approval is valid for a period 20th July 2006 to 20th July 2007.

The Ethics Committee is to be supplied with a status report on the progress of the study at least twice in a year after which the study will be reviewed for the annual re-approval.

The final report on the outcome of the study must be submitted upon study completion. You should seek ethical approval from the TDRC Ethical Review Committee of any amendments.

Please refer to the Ethics Committee's Standard Operating Procedures/ Work procedures for more information regarding applications, amendments, and annual re-approval.

Your study number is **TDRC /ERC/CBU 04-07-/06**

The Committee wishes you and your team every success in the execution of the study. The above has been noted for the Ethics Committee information and records.

Yours Sincerely,
TROPICAL DISEASES RESEARCH CENTRE

Shepherd Khondowe
SECRETARY - TDRC Ethical Review Committee

cc Director
Deputy Director
STC - Chairman

Appendix 7: Application Letter for permission to conduct study in Kitwe District Health Management Board Health Centres

House no. B14,
Copperbelt University,
Jambo Drive, Riverside,
Kitwe.
21st August, 2006.

The District Director of Health,
Kitwe District Health Management Board,
Kitwe.

Dear Sir/Madam

Ref: Request for permission to involve your staff and patients in a study

My name is Nawa Sanjobo. Iam currently a student at the University of Oslo in Norway studying for Master of Philosophy Degree in International Community Health.

Iam in the country at the moment to do fieldwork. I have already been cleared by the University of Oslo for fieldwork as shown in the attached letter. I have also been cleared by the Tropical Disease Research Centre (TDRC) Ethical Committee.

My research will focus on Factors affecting Adherence to Antiretroviral Treatment (ART). The study areas will be in Kitwe and Mpongwe districts, involving health care professionals and patients on antiretroviral treatment (ART).

Iam aware of your organisation's active involvement in supporting ART programmes in Kitwe. Iam therefore requesting your office for permission to involve some of your health staff and patients in my study. The results of this study will be shared with your organisation as a way of enhancing knowledge in the area of ART adherence.

Your assistance in this matter will be highly appreciated.

Yours sincerely,

Nawa Sanjobo

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Appendix 8: Application Letter for permission to conduct study at Kitwe Central Hospital

House no. B14,
Copperbelt University,
Jambo Drive, Riverside,
Kitwe.
21st August, 2006.

The Executive Director,
Kitwe Central Hospital Board of Management,
PO BOX 20969,
Kitwe.

Dear Sir

Ref: Request for permission to involve your staff and patients in a study

My name is Nawa Sanjobo. Iam currently a student at the University of Oslo in Norway studying for Master of Philosophy Degree in International Community Health.

Iam in the country at the moment to do fieldwork. I have already been cleared by the University of Oslo for fieldwork as shown in the attached letter. I have also been cleared by the Tropical Disease Research Centre (TDRC) Ethical Committee.

My research will focus on Factors affecting Adherence to Antiretroviral Treatment (ART). The study areas will be in Kitwe and Mpongwe districts, involving health care professionals and patients on antiretroviral treatment (ART).

Iam aware of your organisation's active involvement in supporting ART programmes in Kitwe. Iam therefore requesting your office for permission to involve some of your health staff and patients in my study. The results of this study will be shared with your organisation as a way of enhancing knowledge in the area of ART adherence.

Your assistance in this matter will be highly appreciated.

Yours sincerely,

Nawa Sanjobo

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Appendix 9: Application letter to amend the approved Ethical Clearance

House no. B14,
Copperbelt University,
Jambo Drive, Riverside,
Kitwe.
21st August, 2006.

The Secretary,
Tropical Diseases Research Centre (TDRC) Ethical Review Committee,
PO Box 71769,
Ndola.

Dear Sir/Madam,

Ref: Amendment to study number TDRC/ ERC/ CBU 04-07-06

Following the approval of my research protocol entitled **'Factors affecting adherence to antiretroviral treatment in Zambia: a qualitative study of patients and health care professionals in Kitwe and Mpongwe districts'**, I would like to change the Mpongwe site to Masaiti.

This change has been necessitated following the approval of my research grant by my sponsors because they would like me to carry out the study in the area they are currently operating from.

The socio-demographic characteristics of Mpongwe and Masaiti districts are similar and therefore, will not affect the outcome of the earlier planned study.

Enclosed herewith is a copy of the approved version of the study from the TDRC Ethical Review Committee.

I will be grateful if my application for this amendment is granted.

Yours Sincerely,

Nawa Sanjobo

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Appendix 10: Amended application letter from TDRC

TROPICAL DISEASES
Tel/Fax 612837

RESEARCH CENTRE
P O Box 71769
NDOLA, ZAMBIA

TDRC ETHICS REVIEW COMMITTEE
IRB REGISTRATION NUMBER: 00002911
FWA NUMBER: 00003729

TDRC/ERC/09/06

9th November 2006

Mr. Sanjobo Naawa
Principal Investigator
Factors affecting adherence to antiretroviral treatment in Zambia: A qualitative study of patients and health care professionals in Kitwe and Mpongwe districts

Dear Mr. Sanjobo Naawa,

RE: Factors affecting adherence to antiretroviral treatment in Zambia: A qualitative study of patients and health care professionals in Kitwe and Mpongwe districts

Reference is being made to your letter dated 31 August 2006 in which you submitted a change of the study site from Mponwe to Masaiti for the above named protocol study number TDRC /ERC/CBU 04-07-/06.

On behalf of the Chairman of the Tropical Diseases Research Centre Ethical Review Committee, I am pleased to inform you that the committee has approved the change of study site.

Please note that the above named protocol should now read as "*Factors affecting adherence to antiretroviral treatment in Zambia: A qualitative study of patients and health care professionals in Masaiti district.' version 2 of 31 August 2006.* Kindly submit a protocol bearing the new name to the committee as soon as possible.

The Committee wishes you every success in the execution of the study. The above has been noted for the Ethics Committee information and records.

Yours Sincerely
TROPICAL DISEASES RESEARCH CENTRE

Shepherd Khondowe
SECRETARY - TDRC Ethical Review Committee

cc Director
STC - Chairman

Appendix 11: Application Letter for permission to conduct study in Masaiti District Health Management Board Health Centres

House no. B14,
Copperbelt University,
Jambo Drive, Riverside,
Kitwe.
11th November, 2006.

The District Director of Health,
Masaiti District Health Management Board,
Masaiti.

Dear Sir/Madam,

Ref: Request for permission to involve your staff and patients in a study

My name is Nawa Sanjobo. Iam currently a student at the University of Oslo in Norway studying for Master of Philosophy Degree in International Community Health.

Iam in the country at the moment to do fieldwork. I have already been cleared by the University of Oslo for fieldwork as shown in the attached letter. I have also been cleared by the Tropical Disease Research Centre (TDRC) Ethical Committee.

My research will focus on Factors affecting Adherence to Antiretroviral Treatment (ART). The study areas will be in Kitwe and Masaiti districts, involving health care professionals and patients on antiretroviral treatment (ART).

Iam aware of your organisation's active involvement in supporting ART programmes in Masaiti. Iam therefore requesting your office for permission to involve some of your health staff and patients in my study. The results of this study will be shared with your organisation as a way of enhancing knowledge in the area of ART adherence.

Your assistance in this matter will be highly appreciated.

Yours sincerely,

Nawa Sanjobo.